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Version: Version of Record

Link(s) to article on publisher's website:
<http://dx.doi.org/doi:10.21954/ou.ro.0000ed59>

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**THE MEANING OF EUTHANASIA:
CATHOLIC TEACHING AND NURSES' PRACTICE IN
THE CARE OF THE DYING**

THESIS FOR THE AWARD OF THE DEGREE OF PH.D

2010

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MARYVALE INSTITUTE

AND

THE OGILVIE INSTITUTE

Date of Submission: 8 October 2010
Date of Award: 22 November 2010.

**THE MEANING OF EUTHANASIA: CATHOLIC
TEACHING AND NURSES' PRACTICE IN
THE CARE OF THE DYING**

A NURSING and MORAL THEOLOGICAL STUDY

**An examination of the meaning of euthanasia and an exploration of nurses'
experiences of how decisions are made on end-of-life care in private care
homes in the light of Christian moral principles, as rooted in
Catholic teaching.**

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Acknowledgements

I would like to thank all those who have helped me during the course of writing this thesis. First, I owe much gratitude to Canon George Woodall, M.A., S.T.D., J.C.L., my Director of Studies who has supported me through the many difficulties of my studies. His patience, direction and assistance have been greatly appreciated and have enabled me to write this thesis with clarity. I also express my thanks to my supervisor, Professor Cecily Begley, Professor of Nursing and Midwifery Studies, Trinity College, Dublin for her critical comments, wisdom, encouragement and inspiration.

I wish to give thanks to Professor Alan McClelland, former Research Degree Co-ordinator at Maryvale Institute, Birmingham and to Dr. Petroc Willey present Research Degree Co-ordinator at Maryvale Institute, Birmingham and to Reverend Anthony Schmitz, former Director of The Ogilvie Institute, Aberdeen.

This thesis would not have been possible without the contribution from the eleven registered nurses whose experiences lie at the very heart of this study. I am deeply grateful for the time which they gave and for their willingness to contribute to this important research. During the time I spent with them I was impressed with their devoted care and the love which they bestowed on their elderly patients. They truly are an example of the very best of professional nurses. I must also thank their care home managers who supported them and enabled them to participate in this study. Their contribution as gatekeepers was invaluable.

I give a special thanks to Paul James, librarian, Maryvale Institute, Birmingham and I thank all who have assisted me in the libraries of The Ogilvie Institute, Aberdeen, The former Linacre Centre, London, The Queen Mother Library at the University of Aberdeen, The Robert Gordon University, Aberdeen, The Heythrop College Library in London.

I thank the Benedictine Community at Pluscarden in Elgin and the Bridgettine Sisters at The Maryvale Institute in Birmingham for their prayerful support over these years.

I have been supported by many close friends and I am very grateful for their commitment to our friendship. I would like to mention two friends in particular Dr. Gordon Higson, who has since died and who encouraged me to commence my studies and Dr. Winifred Eboh who has given valuable comments and asked searching questions regarding the subject of my thesis and given me her friendship and support.

I am grateful to my parents; sadly my beloved father died before the completion of this work. I thank my sister Hazel and all my family for all their encouragement and prayers.

Finally, to my husband Rick, who has borne great patience and understanding, has been a source of strength and has sustained me with moral support and love throughout my entire studies, I thank him for always having been there for me.

ABSTRACT

The Meaning of Euthanasia: Catholic Teaching and Nurses' Practice in the Care of the Dying

This research study has contributed to the body of knowledge, new knowledge in applying Christian and Catholic moral theological principles to how nurses make end-of-life decisions and the possibility of how they could be involved were euthanasia to be legalised and how this could impact on the Christian nurse's role in caring for the patient. In addition the study has contributed new information on the experiences of one group of nurses working in care homes and how they make end-of-life decisions. The study also confirms research previously undertaken on end-of-life decision-making and the experiences of other nurses in the United Kingdom as well as other countries.

Using a qualitative design as a framework, an investigation was undertaken to explore the experiences of eleven qualified nurses from care homes within one geographical area in the north of Scotland, and how they made decisions on end-of-life care. A review of nursing and moral philosophy and moral theology literature is undertaken to place the empirical study within the context of contemporary definitions of euthanasia, current legislation and key debates. The empirical research is evaluated to determine how any legalisation of euthanasia in the United Kingdom could impact on Christian nurses' decision-making and their roles in caring for the patient, in the light of Christian moral principles.

The originality of the research lies in the exploration of the phenomenon with a particular group of nurses and the relation of the study findings to Christian moral principles.

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THE MEANING OF EUTHANASIA:
CATHOLIC TEACHING AND NURSES' PRACTICE IN
THE CARE OF THE DYING

INTRODUCTION

The Topic Being Studied

My intention is to examine the meaning of euthanasia and to explore nurses' experiences of end-of-life decision-making in private care homes. The aim is to undertake this discussion in the light of Christian moral principles, specifically as rooted in Catholic teaching. The original title of this study was "The Legalisation of Euthanasia: The Impact on Nurses and Their Practice" and, under that title the empirical study whose findings are presented and discussed in chapters three, four, five and seven was conducted. However, it was judged that the revised title was a more accurate one for the study as a whole.

Justification of the Topic

Traditionally, the Christian viewpoint is that life is sacred and no-one has the right directly and deliberately to destroy an innocent human being.¹ In the encyclical 'Evangelium vitae,' Pope John Paul II calls upon society to defend "the sacred value of human life from its very beginning until its end."² Nurses are at the very forefront of caring for life, right up until the moment of death and, inherent within their code of practice internationally, is a moral and legal obligation to defend the right to life.³ In following a Christian moral code, Christian nurses could be affected by any change in the law that would legalise euthanasia and it is important to determine what this could entail.

¹ Catechism of The Catholic Church (Geoffrey Chapman, London, 1994) n. 2258. [Hereafter, CCC].

² Evangelium vitae, n.2.

³ International Council of Nurses. International Code of Ethics for Nurses [Online] (2006).

Originality of the Study

No specific study of the theme appears to have been made. I made a meticulous literature search prior to undertaking the study and this revealed that some research had been undertaken on end-of-life issues in various settings. There are also several publications addressing the ethical principles that are relevant to end-of-life issues. There is literature on the subject of euthanasia and there is some research in other parts of the world on nurses' attitudes to aspects of the euthanasia debate.

However, no research has been undertaken on nurses' experiences of end-of-life decision-making in care homes with the purpose of discussing such experiences in the light of Christian moral principles. Hence, the originality of this work lies in the exploration of this phenomenon with a particular group of nurses and the relation of the study's findings to Christian moral principles. This is especially relevant to the nursing profession and significant for the euthanasia debate at a time when euthanasia is not legal in the United Kingdom, but where its possible legislation is under discussion.

The Reason for the Choice of Philosophical and Theological Sources.

It is not my intention to make an exhaustive study of all the philosophical and theological sources. I have deliberately selected four authors prominent in philosophical bioethics, in which to explore what euthanasia means to them: Singer querying the specificity of human beings, Engelhardt addressing pluralistic societies and Beauchamp and Childress being a principal source of reference for the nursing profession on ethical questions and Harris addressing ethical dilemmas that arise in medical ethics.

I have deliberately undertaken a Christian approach to the research because the law in the United Kingdom is derived from Christian principles. Furthermore, within the Catholic Church the large body of doctrine and principles related to medical ethics justifies concentration upon Catholic theology. This is appropriate to the empirical research, which was undertaken in Scotland, because there is a large Catholic population there.

The Structure of the Dissertation

The structure of the thesis, comprising eight chapters, is as follows:

Chapter One - examines the meaning of euthanasia in the United Kingdom and other parts of the world and presents definitions of euthanasia used in the contemporary context, in medical and nursing literature, from a secular perspective and from a Christian perspective, incorporating texts from the Magisterium, the official teaching body of the Catholic Church.

Chapter Two - In this chapter, I have reviewed a selection of research studies, which relate to nurses' attitudes, beliefs, roles and experiences when dealing with end-of-life issues and euthanasia.

Chapter Three – This chapter sets out the issues encountered in designing and conducting a qualitative interview-based study and the importance of ensuring rigour in qualitative research. Ethical clearance was given for this investigation by The Open University Human Participants and Materials Ethical Committee. Eleven nurses were recruited for the research study and each one was interviewed using an interview guide as a tool. This took place

within the participant's clinical area and with the full support of the nurse-manager from each area. Included in the appendices related to this chapter are detailed descriptions of the coding process and the codes that were generated from the data.

Chapter Four – In this chapter the findings from the qualitative investigation are presented. When analysing the data, three themes emerged which characterised the nurses' experiences, that of ensuring a good death, ensuring the provision of hydration and nutrition at the end of life, ensuring that medication is appropriate to the patient's needs. These are discussed within the eight categories identified and labelled during the research analysis.

Chapter Five – This chapter discusses the findings of the empirical research reported in chapter four and their significance in relation to published debates and wider literature in the field of nursing research on care of the dying.

Chapter Six – This chapter presents an exposition of Catholic doctrinal teachings and their implications for nurses who are Christian Catholics in relation to end-of-life decision making and euthanasia. This is written in three stages, 1) Euthanasia, 2) Withdrawing and withholding artificial nutrition and hydration, 3) Questions of co-operation and of conscientious objection.

Chapter Seven - This chapter integrates the study findings with the nursing and moral philosophy and theology literature and is examined to determine their similarities and divergences, whether euthanasia in some forms may be acceptable and not. These are

further examined to determine what the legalisation of euthanasia could mean for Christian nurses, in the light of Christian moral principles.

Chapter Eight - The final chapter is concerned with summarising and concluding the research study and includes new contribution to the body of knowledge, the limitations in conducting the whole thesis, the results of adopting a Christian Catholic approach, recommendations for the future in the context of national developments which seek to improve the quality of care at the end-of-life in care homes and other settings.

Integrity of the Researcher

Every researcher operates with certain presuppositions and it is important to expose these presuppositions, for there is always the potential for bias in any research. My point of departure for this research is my understanding of what the Catholic Church teaches and my personal experience of nursing new born disabled infants where the decision was made by others to allow them to die. However, it is necessary and proper that these presuppositions be critically examined during the research itself and in the light of the research. My presuppositions were these, that no innocent human being should be deliberately and directly killed and there are some procedures that may be considered a burden to the dying patient that may be discontinued, not with the intent to kill, but to accept that death is a natural process and that there is a time to die naturally. However, any decision to discontinue procedures should only be made by the dying patient or his/her relatives. Pain relieving medication should be used, even at the risk of shortening the life of the dying patient to ensure a comfortable and dignified death and nutrition and hydration should always be provided to sustain the life of the patient.

I documented these pre-suppositions prior to commencing the study and endeavoured, throughout the empirical phase, to avoid making my opinions known to the nurse participants. During the analysis phase I tried to remain objective in my interpretation of the participants' words and sought peer review and debriefing of the material to ensure my objectivity. I am confident that I have succeeded in remaining objective and professional throughout the research process.

CHAPTER ONE

THE MEANING OF EUTHANASIA

1.1 Introduction

This chapter explores the meaning of euthanasia in the United Kingdom and other parts of the world used in the contemporary context, in medical and nursing literature, from a secular perspective, from a Christian perspective incorporating texts from the Magisterium, the official teaching body of the Catholic Church, and examines the possible clinical implications for clinicians (nursing and medical) when making end-of-life decisions.

1.2 Nursing Definition of Euthanasia

Although nurses are involved in end-of-life decision-making and so perhaps in euthanasia, it is not always clear what is meant by euthanasia.¹ One definition considers euthanasia as follows:

“The deliberate ending of life of a person suffering from an incurable disease; this can be voluntary or involuntary.”²

This definition refers to “incurable disease” being the reason for advocating euthanasia, the ‘intention’ being to end the person’s life ‘deliberately.’ Euthanasia is described as being only ‘voluntary’ (with the wishes of a competent patient) or ‘involuntary’ (against the wishes of a competent patient). Nursing decisions on end-of-life care also concern

¹ Berghs, M., Dierckx de Casterlé, B., Gastmans, C. “The Complexity of Nurses’ Attitudes Towards Euthanasia: A Review of The Literature,” Clinical Ethics [Online] (2005) 31.

² Weller, B., ed., Baillière’s Nurses’ Dictionary for Nurses and Health Care Workers, 25th ed., (Baillière Tindall Elsevier Ltd., Edinburgh, 2009) 144.

incompetent patients who cannot express their wishes. If euthanasia is classified as 'voluntary' or 'involuntary, it might be well to add a category of 'non-voluntary' in order to distinguish different ways in which euthanasia can be conducted. Those who incorporate only 'voluntary' into a definition, thereby limit what would be classified as euthanasia.

1.3 Definition of Euthanasia in The United Kingdom.

1.3.1 A Contemporary Definition of Euthanasia

The following contemporary definition was put forward to the researcher by the South West Multi-centre Research Ethics Committee on June 12, 2003, in relation to an earlier quantitative research proposal, which would enable nurses, if asked, to base their views on a definition which is generally accepted within English law:³

"Euthanasia refers to the practice of ending another person's life with the intention of ending their suffering. It is sometimes described as the practice of bringing about a "good" or "quiet" death. It can be classified as:

- involuntary (against the wishes of a competent person);
- voluntary (with the wishes of a competent person);
- non-voluntary (where the individual is incompetent).

These categories may be sub-divided as active (a positive act that causes the death) or passive (an omission or failure to act.)⁴

"Active euthanasia is murder.⁵

R v Cox (1992)."⁶

however,

³ South-West Multi-Centre Research Ethics Committee. Response Form to Sylvia Hoskins. MREC/03/6/55. [12 June 2003].

⁴ Maclean, A. Briefcase on Medical Law (Cavendish Publishing Ltd., London, 2001) 93.

⁵ Ibid., 93.

⁶ Ibid., 93.

“Where death is not ‘intended,’ a positive act (for lawful purpose) that also hastens the death of the patient is lawful. R V Bodkin Adams (1957).”⁷

“Passive euthanasia may be lawful

It is lawful to accede to a competent patient’s wishes not to be treated. Re T (Adult: Refusal of Medical Treatment) (1992) CA.”⁸

“It is lawful not to treat an incompetent patient providing it is not contrary to the patient’s best interests. Re J (A Minor) 1990 CA.”⁹

“Artificial nutrition and hydration are forms of medical treatment that maybe withheld or withdrawn where it is not contrary to the patient’s best interests. Airedale NHS Trust v Bland (1993) HL.”¹⁰

This contemporary definition, considered legally reliable in recent years could possibly assist nurses in their decision-making. This is examined further in the following three case studies, the first involving active euthanasia, the second and third passive euthanasia, one in England and one in Scotland where there are differences between the legal systems.

1.3.1.1 Example One: “Active Euthanasia is Murder.” R. v Cox (1992)¹¹

Mrs. Lillian Boyes, was admitted to hospital suffering from a terminal illness which caused her extreme emotional suffering and physical pain.¹² Mrs. Boyes refused any active medical treatment and repeatedly requested that Dr. Cox and others end her suffering and pain by a lethal injection. Dr. Cox administered pain-relieving medication to alleviate her suffering. He later administered two ampoules of potassium chloride, a

⁷ Ibid., 93.

⁸ Ibid., 95.

⁹ Ibid., 95.

¹⁰ Ibid., 98.

¹¹ Kennedy, I., Grubb, A. “R. v Cox (1992) 12 BMLR38 (Winchester CC).” in Grubb, A., ed. Medical Law, 3rd ed. (Butterworths, London, 2000) 1963-1966.

¹² Ibid., at 1963.

substance when given in its purity is lethal and which has no pain-relieving or sedative properties. Within a matter of minutes, Mrs. Lillian Boyes died.¹³

Evidence given by Staff Nurse Creasey included her professional opinion that Mrs. Boyes had no longer than a few hours to live that morning.¹⁴ If, by giving potassium chloride, Dr. Cox intended to hasten Mrs. Boyes's death, then he was guilty of killing the patient. If death was not intended and he administered analgesia to relieve her pain, even at the risk of shortening her life, then he would not be guilty of attempted murder.¹⁵ Dr. Cox was found guilty of attempted murder.¹⁶

This example demonstrates the difference between an intention to end the patient's pain and an intention to end the patient's life. In this case, Dr. Cox's actions were judged by the court to have been based on an 'intention' to end Mrs. Boye's life. The degree to which Nurse Creasey co-operated is dependent on her awareness of a) Dr. Cox's intention, b) the potential lethal nature of potassium chloride, or whether she challenged Dr. Cox on his decision or agreed with his actions.

1.3.1.2 Example Two: "Artificial Nutrition and Hydration are Forms of Medical Treatment That May be Withheld or Withdrawn Where It Is Not Contrary to The Patient's Best Interests." ¹⁷

¹³ Ibid. at 1963, 1965.

¹⁴ Ibid. at 1965.

¹⁵ Maclean, A. Briefcase on Medical Law (2001) 93, 94.

¹⁶ Kennedy, I., Grubb, A. "R. v Cox (1992) 12 BMLR38 (Winchester CC)." in Grubb, A., ed. Medical Law, 3rd ed. (2000) 1964.

¹⁷ Maclean, A. Briefcase on Medical Law (2001) 98.

1.3.1.2.1 In England: Airedale NHS Trust v Bland (1993) HL.”¹⁸

Anthony (Tony) Bland, aged twenty-one years old was diagnosed as being in a “persistent vegetative state” (PVS), with no hope of recovery.¹⁹ Since he was judged to be non-competent, legal proceedings were initiated to discontinue all life sustaining treatment, including hydration and nutrition by artificial means which were judged not in his interests and therefore to be removed.²⁰ In summarising the case, Lord Mustill acknowledged the problems for nurses in making clinical decisions on end-of-life care and the difficulties this action could present to those who believed firmly in the sanctity of life.²¹ Removing a tube which provides life sustaining treatment is an ‘action’ with a specific ‘intention’ to end the patient’s life and some nurses might consider this to be ‘active’ euthanasia.

1.3.1.2.2 In Scotland: Law Hospital NHS Trust v Lord Advocate and Another (1996).²²

In January 1992, Janet Johnstone was admitted to Law Hospital, Carlisle where she stayed in a ‘persistent vegetative state’ for three years.²³ In March, 1994, her husband and daughter requested that her artificial feeding should be discontinued.²⁴ By February 1995, a review by three consultant neurosurgeons and a nurse confirmed that there was no prospect of recovery.²⁵ The hospital, supported by Mrs. Johnstone’s family, sought a

¹⁸ Ibid., 98.

¹⁹ Crown Court: Family Division. “Judgment: Airedale NHS Trust-v-Bland Family Division [1992] 2 WLR 316 (19 November 1992).” Lawindexpro – Case Law [Online].

²⁰ Ibid.

²¹ Ibid.

²² Hunter, R., ed. “Law Hospital NHS Trust v Lord Advocate (Lord President)” in The Scottish Council of Law Reporting: 1996 Session Cases (Green, W., The Scottish Law Publisher, Edinburgh, 1997) 301-330.

²³ Report of Lord Cameron of Lochbroom to The Inner House of The Court Of Session in The Cause Law Hospital NHS Trust (Pursuers) against Lord Advocate and Others (Defenders) (Court of Session Edinburgh, 1996) (9 January) 1-35 at 2-3, 4.

²⁴ Ibid. at 8.

²⁵ Ibid. at 9. [Consultant Neurosurgeons: Mr. Philip Harris. Drs. Grant, Metcalf; Nurse: Sister Davidson].

‘declarator,’ modelled on the declarations in *Airedale NHS Trust v Bland* [1993], as to the legal consequences of terminating artificial feeding.²⁶

The court’s opinion was that Mrs. Johnstone’s life was being artificially prolonged and that there was no medical justification for continuing her life, nor was it in her interest.²⁷

They stated that, under Scots law, the artificial feeding tube could be considered as an assault on Mrs. Johnstone.²⁸ Her artificial feeding was withdrawn on 16 May 1996 with her subsequent death.

These two cases demonstrate that nurses should be aware of the differences in law in the United Kingdom where in England, the feeding tube ‘could’ be removed lawfully and in Scotland, it is possible that the feeding tube ‘should’ be removed. Despite differences in law, by removing an artificial feeding tube, a positive act of commission, the intention is to allow the patient to die and nurses could perceive this as ‘active’ euthanasia.

1.3.2 British Medical Association (BMA): Position Statement: Euthanasia and Assisted Suicide (2009).

The BMA’s annual conference in Belfast on 29, June 2006, voted overwhelmingly against legalising physician assisted suicide and euthanasia.²⁹ As of 20 February, 2009, the current policy is that the BMA opposes the legalisation of physician-assisted suicide, voluntary euthanasia and non-voluntary euthanasia and advocates palliative

²⁶ Hunter, R., ed. “Law Hospital NHS Trust v Lord Advocate (Lord President)” in The Scottish Council of Law Reporting: 1996 Session Cases (1997) 301-330 at 301.

²⁷ Ibid. at 316, 321.

²⁸ Report of Lord Cameron of Lochbroom To The Inner House of The Court Of Session In The Cause Law Hospital NHS Trust (Pursuers) against Lord Advocate and Others (Defenders) (1996) (9 January) 1-35 at 24-25.

²⁹ British Medical Association “Policy Group: Annual Representative Meeting, 2006” Policies [Online] (2006).

care as a means to allow patients to die with dignity.³⁰ They also insist that in the event that euthanasia were legalised, there should be, “a clear demarcation between those doctors who would be involved in it and those who would not.”³¹ The BMA consider artificial nutrition and hydration as medical treatment and, therefore, when it ceases to provide a ‘net’ benefit, or is judged not in the patient’s best interest, it may be withdrawn.³²

This position statement defines euthanasia as being ‘voluntary’ and ‘non-voluntary,’ but makes no mention of ‘involuntary euthanasia,’ as if it were considered not to be euthanasia. Less clear is what is meant by ‘net benefit’ or ‘in the patient’s best interest’ where this involves the withdrawal or withholding of artificial nutrition and hydration.

1.3.3 Scottish Council on Human Bioethics: Position Statement: Euthanasia (2010).

The Scottish Council on Human Bioethics is an independent, non-partisan, non-religious council, composed of professionals from disciplines associated with medical ethics including physicians, lawyers and ethicists and subscribes to the principles set out in the United Nations Declaration of Human Rights (1948).³³ They define euthanasia as:

“...an intervention (an intentional act or omission) to end the life of a person by someone else who believes that it would be preferable for the person to die than to continue living. The key motive is intent.”³⁴

It can be ‘active’ where the person’s life is ended by the use of drugs or ‘passive’ where life sustaining treatment, nutrition and/or hydration are withheld or withdrawn with the

³⁰ British Medical Association. “Assisted Dying – A Summary of The BMA’s Position” [Online] (2009).

³¹ Ibid.

³² British Medical Association. “End-Of-Life Decisions” [Online] (2009).

³³ Scottish Council on Human Bioethics (SCHB) [Online] (2010).

³⁴ Scottish Council on Human Bioethics (SCHB). “Position Statement: Euthanasia” [Online] (2010).

intention of hastening the patient's death.³⁵ Euthanasia that is voluntary and based on the patient's autonomous request is distinguished from mercy-killing. However, where someone else makes a decision that a person's life is not worth living, the voluntariness of the patient's consent could be in question.

1.3.4 European Association for Palliative Care Ethics Task Force Definition: Euthanasia and Physician Assisted Suicide (2002).

The European Association for Palliative Care (EAPC) Task Force has adopted the following definitions on euthanasia and physician assisted suicide:

“Euthanasia is killing on request and is defined as: a doctor intentionally killing a person by the administration of drugs, at that person's voluntary and competent request.

Physician-assisted suicide is defined as: a doctor intentionally helping a person to commit suicide by providing drugs for self-administration, at that person's voluntary and competent request.”³⁶

They consider that this definition does not entail any value judgement and that,

“the expression “killing on request” is, in connection with euthanasia, a technical description of the act, based upon the procedure used – usually an injection of a barbiturate to induce coma, followed by the injection of a neuromuscular relaxant to stop respiration, causing the patient to die.”³⁷

“Withholding futile treatment; withdrawing futile treatment; ‘terminal sedation’ (the use of sedative medication to relieve intolerable suffering in the last days of life) are judged to be neither euthanasia nor assisted suicide.”³⁸

The “medicalized killing of a person without the person's consent, whether non-voluntary (where the person is unable to consent) or

³⁵ Ibid.

³⁶ Materstvedt, L., Clark, D., Ellershaw, J., Førde, R., Gravgard, A., Müller-Busch, H., Porta i Sales, J., Rapin, C. “Euthanasia and Physician-Assisted Suicide: A View From An EAPC Ethics Task Force.” Palliative Medicine (2003) 97-101 at 98.

³⁷ Ibid., 97-98.

³⁸ Ibid., 98.

involuntary (against the person's will), is stated to be not euthanasia, but murder ...”³⁹

“...the frequently used expression ‘voluntary euthanasia’ should be abandoned since it is by implication, and incorrectly suggests that there are forms of euthanasia that are not voluntary.”⁴⁰

... a distinction is sometimes drawn between so-called ‘active’ and ‘passive’ euthanasia. It is our view that this distinction is inappropriate.”⁴¹

On our interpretation, as well as according to the Dutch understanding, euthanasia is active by definition and so ‘passive’ euthanasia is a contradiction in terms – in other words, there can be no such thing.”⁴²

In addition, the Ethics Task Force clearly differentiate between euthanasia and ‘terminal’ or palliative’ sedation, marking the distinction as:

“In terminal sedation the *intention* is to relieve intolerable suffering, the *procedure* is to use a sedating drug for symptom control and the successful *outcome* is the alleviation of distress.

In euthanasia the *intention* is to kill the patient, the *procedure* is to administer a lethal drug and the successful *outcome* is immediate death.”⁴³

This definition offers a practical explanation which may assist clinicians in making end-of-life decisions especially pertaining to palliative care. Less clear, for withdrawal and withholding treatment, is what is considered “futile” and whether or not this is deemed to include artificial hydration and nutrition.

1.4 Assisted Suicide in The United Kingdom

Assisted suicide differs from suicide in that another person is involved in assisting the person to die. Some consider that there is no difference between ‘assisted suicide’ and ‘euthanasia.’

³⁹ Ibid., 98.

⁴⁰ Ibid. 98

⁴¹ Ibid. 98.

⁴² Ibid., 98.

⁴³ Ibid., 98.

1.4.1 A Nursing Definition: Assisted Suicide

In one nursing definition, 'assisted suicide' is defined in relation to the competency of the person and the autonomous desire to end his/her life, but requires assistance.⁴⁴ Physician-assisted suicide occurs when a doctor gives the help requested."⁴⁵ However, this definition does not state that the patient should be suffering or terminally ill and s/he could have a treatable condition. In addition, even though deemed competent, the patient may be unable to make a rational decision due to illness.⁴⁶

In a Nevada definition, 'provision of information' is considered a means of enabling the patient die; competency, the 'voluntariness' of the request and the patient's terminally ill status are further conditions.⁴⁷

Similar to the Nevada nurses' definition, in Asch's study of critical care nurses in the United States, the provision of 'explicit advice' to patients about how to commit suicide is also included in the definition of euthanasia and assisted suicide, which is, the administration of medication as a means to enable the act with the intention of causing or hastening the patient's death.⁴⁸ This definition specifies that it does not include 'withdrawing a mechanical ventilator,' even though it is recognised that this might result in the patient's death and, as the following example demonstrates, nurses could perceive a request for the withdrawal of such, as a request for assisted suicide.

⁴⁴ Clarke, C. "Ethics and The End Of Life" in Holland, S. ed., Introducing Nursing Ethics: Themes In Theory and Practice (2004) 49-64 at 58-59.

⁴⁵ Ibid., at 59.

⁴⁶ Edwards, S. Nursing Ethics: A Principle-Based Approach, 2nd ed. (Palgrave Macmillan, Basingstoke, 2009).

⁴⁷ Kowalski, S. "Nevada Nurses' Attitudes Regarding Physician-Assisted Suicide." Clinical Nurse Specialist [Online] (1997) 11 (13).

⁴⁸ Asch, David A. "The Role of Critical Care Nurses in Euthanasia and Assisted Suicide." The New England Journal of Medicine [Online] (1996) 334 (21).

1.4.2 Example: “Ms. B and an NHS Hospital Trust [2002] EWHC 429”⁴⁹

Ms. B, a middle-aged woman, physically incapacitated due to a debilitating illness had become a tetraplegic and was dependent on life-long ventilation. She regarded the ventilator as invasive treatment and she wished it to be withdrawn. English law recognises a competent patient’s right to refuse treatment, but whether Ms. B had all the information to make an informed decision and whether she was capable of making a decision, given her complicated illness, was unclear.⁵⁰ After being deemed capable, she then requested that medical treatment cease and her ventilator be withdrawn.⁵¹ The court determined that Ms. B had a right to cessation of treatment which could override the concerns of the medical and nursing staff who regarded her request as a request to kill her.⁵²

Under the American definition last noted, this action would not constitute assisted suicide or euthanasia, but the reaction of some of the staff may suggest that they might not have agreed. Ms. B recognised the doctors’ rights to refuse personally to withdraw treatment, but suggested that they refer her to someone else. Dr. C., an anaesthetist, felt compromised by a request to kill, since her duty as a doctor was to preserve life and she could not envisage the possibility of switching off the life support where someone was not in the process of dying.⁵³

1.4.3 Scottish Council on Human Bioethics: Passive Suicide.

The Scottish Council on Human Bioethics (SCHB) defines ‘passive suicide’ as:

⁴⁹ The High Court of Justice: Family Division. “Approved Judgment: Ms. B and An NHS Hospital Trust [2002] EWHC 429 (Fam)” The Court Service – Family Division – Judgment [Online] (2002).

⁵⁰ Ibid.

⁵¹ Ibid.

⁵² Ibid.

⁵³ Ibid.

“suicide without an active intervention, whereby a person makes a conscious and contemporaneous decision not to accept or to withdraw from life-sustaining treatment with the aim of hastening his or her own death. Passive suicide recognises the right of a patient not to accept a medical intervention even if it may save his or her life.”⁵⁴

This definition illuminates the complexities in Ms B’s case where nurses could interpret her decision as ‘passive suicide,’ ‘assisted suicide,’ or ‘passive euthanasia.’

1.4.4 Scottish Council on Human Bioethics: Position on Assisted Suicide (2009).

The SCHB define ‘assisted dying’ as a term used to cover both ‘assisted suicide’ and ‘euthanasia.’⁵⁵ ‘Assisted suicide’ is defined as “an act whereby a person aids, abets, counsels or procures a suicide or an attempted suicide of another individual”; ‘physician assisted suicide’ is defined as “the act whereby a physician prescribes a lethal medication to a person, but the person administers the dose himself or herself.” However, in some clinical situations ‘assisted dying’ has a more general meaning to ensure that the patient has a comfortable and pain-free death. The problem for nurses is that there is no explanation of what the real difference is between assisted dying, assisted suicide, physician-assisted suicide and euthanasia. This is evidenced in Lord Joffe’s proposed Bill where the term ‘assisted dying’ is used to mean ‘assisted suicide.’

1.4.5 House Of Lords: Assisted Dying for The Terminally Ill Bill [HL]

In England, on May 12, 2006, The House of Lords rejected Lord Joffe’s “Assisted Dying for The Terminally Ill Bill.”⁵⁶ The purpose of the Bill, was to allow physicians to provide the means to end a patient’s life where he autonomously requests it. Assisted dying is defined as:

⁵⁴ SCHB. “Position Statement: Assisted Suicide.” [Online] (2009).

⁵⁵ Ibid.

⁵⁶ House of Lords. “Assisted Dying For The Terminally Ill Bill [HL]” [Online] (2006).

- (a) a physician to assist a patient who is a qualifying patient to die,
- (i) by prescribing such medication, and
 - (ii) in the case of a patient for whom it is impossible or inappropriate orally to ingest that medication, by prescribing and providing such means of self-administration of that medication,
- as will enable the patient to end his own life,
- (b) a person who is a member of a health care team to work in conjunction with a physician ...”⁵⁷

This definition does not clarify what means are to be used to self-administer if the patient cannot ingest medication orally, since some nurses might consider that they are being asked to assist in euthanasia, nor does it state what exactly is required from nurses when working in conjunction with a physician.⁵⁸

1.4.6 Margaret MacDonald, MSP: The Proposed End-of-Life Choices (Scotland) Bill: Consultation Document (2008).

In Scotland, in 2008, Margo McDonald (MSP) proposed a private member’s Bill “to clarify the laws in Scotland relating to the assistance given to end the life of a person requesting such help before death would occur naturally.”⁵⁹ In her Bill, she proposed three categories for consideration:

1. “Patients enjoying otherwise satisfactory health but with degenerative, irreversible conditions...
2. Patients who unexpectedly become incapacitated to a degree they find intolerable ...

⁵⁷ Ibid.

⁵⁸ Ibid.

⁵⁹ MacDonald, M. “The Proposed End of Life Choices (Scotland) Bill: Consultation Document 2008.” [Online] (2008).

3. Patients who are not terminally ill, suffering from a degenerative condition, or unexpectedly incapacitated but who find their life to be intolerable ...⁶⁰

Nurses would need clarification of the term ‘incapacitated’ since the condition might not be permanent and the term ‘intolerable’ is unreliable especially where the patient is depressed or suffering from pain and can be treated successfully.

1.4.7 Lord Falconer of Thoroton: Coroners and Justice Bill: Amendment 173.

In June, 2009, the House of Lords defeated an amendment to the Coroners and Justice Bill, from Lord Falconer of Thoroton (the former Attorney General), to remove any possibility of prosecution of a person who encourages, enables or assists someone to travel to a country outside the United Kingdom where ‘assisted dying’ is lawful, for the purpose of assisting with their suicide.⁶¹ The proposal was limited to the ‘terminally ill,’ meaning “an illness, disease or condition which is inevitably progressive and fatal and which cannot be reversed by treatment.”⁶²

Unlike Margo MacDonald’s proposed Bill, the proposal requires that doctors are necessary only to confirm that the patient has full capacity to make a decision. However, the ‘fatality’ of the illness is not set within a pre-determined time-span, therefore it is possible that this definition could apply to any chronic ‘illness’ and patients may be pressurised by well meaning relatives to seek ‘assisted suicide’ earlier than desired.

⁶⁰ Ibid.

⁶¹ Lord Falconer of Thoroton, “Coroners and Justice Bill: Amendment 173” in, “Lord Hansard Text for 7 Jul 2009” [Online] (2009).

⁶² Ibid.

1.4.8 Responses and Comments on Consultation Documents.

The British Medical Association reaffirmed its opposition to euthanasia, assisted suicide and physician-assisted suicide, in response to the proposed Coroners and Justice Bill on July, 2009, and, in response to the proposed “End-of-Life Assistance (Scotland) Bill” on 21 January, 2010.⁶³

The Scottish Council for Human Bioethics (SCHB) re-affirmed its opposition to euthanasia and assisted suicide, on July 30, 2009, in response to the Law Lords’ decision relating to Debbie Purdy’s appeal that her husband should not be prosecuted if he accompanied her to the Dignitas Clinic in Switzerland where she could access assisted suicide and, on 23 September 2009, in response to the guidelines issued by the Director of Public Prosecutions in England and Wales on the possibility for persons to help individuals travel to Switzerland to access assisted suicide.⁶⁴

On February 25, 2010, Keir Starmer, the Director of Public Prosecutions in England and Wales, issued new guidelines for cases where a person helps an individual travel to Switzerland to access assisted suicide. The policy focuses on the ‘motivation’ of the person assisting, and whether they assist for compassionate reasons or otherwise.⁶⁵

⁶³ British Medical Association. “Newswire Article: BMA Comments on End-of-Life Assistance (Scotland) Bill” [Online] (2010); British Medical Association “Newswire Article: BMA Reaffirms Opposition to Assisted Suicide.” [Online] (2009) (1 July). [Statement made by Dr. Brian Keighley, Deputy Chairman].

⁶⁴ SCHB “Press Release: Ms. Debbie Purdy Assisted Dying Proposals.” [Online] (2009); SCHB “Press Release: Director of Public Prosecutions – Assisted Suicide Proposals.” [Online] (2009).

⁶⁵ The Crown Prosecution Service. “Policy for Prosecutors in Respect of Cases of Encouraging or Assisting Suicide.” [Online] (2010).

1.4.9 Royal College of Nursing: Position on Assisted Suicide

The Royal College of Nursing decided on 24th July, 2009, to change its stance on legalising assisted suicide, from one of opposition to one of neutrality.⁶⁶ Whilst assisted suicide remains against the law, nurses would not be at liberty to discuss this with their patients except to say that it is illegal. The position remains current as of August, 2010.

1.4.10 Nursing and Midwifery Council: Response to The Royal College of Nursing

In recognising the emotional issues concerned with ‘assisted suicide,’ the Nursing and Midwifery Council, the United Kingdom nursing regulatory body, reminded nurses that assisting the suicide of a patient, or giving information or advice on assisted suicide, is against the law and that they are personally accountable for their actions.⁶⁷ This was reaffirmed on September 24, 2009, in response to the release of the new Crown Prosecution Service Guidelines, and remains the current position in August, 2010.⁶⁸

1.5 Definitions of Euthanasia in Other Countries in Europe

1.5.1 Switzerland

In Switzerland, ‘intentional killing’ is not necessarily synonymous with murder, but is regarded as aggravating circumstances which may lead to murder; or mitigating

⁶⁶ Royal College of Nursing. (RCN) Assisted Suicide Consultation [Online] (2009). [The consultation opened on 16 February, 2009, and closed on 22nd May, 2009. Out of approximately 377,000 RCN members, 1,265 detailed responses were sent to the RCN. 1,247 of these were from individual members and the remaining 18 were from groups of members such as branches and forums. 49% of the 1,265 responses supported assisted suicide. 40% of the 1,265 responses were in opposition to assisted suicide. The remaining submissions were either neutral on the issue (9%) or failed to record a position (1%). Based on these results and following the decision by Council the College now neither supports nor opposes a change in the law to allow assisted suicide. (Email to Sylvia Hoskins, from Edward Grant, Royal College of Nursing, 7 September 2009).

⁶⁷ Nursing and Midwifery Council (NMC). “NMC Response to RCN Decision on Assisted Suicide.” [Online] (2009).

⁶⁸ Nursing and Midwifery Council. “Guidelines for Prosecutors on Assisted Suicide” [Online] (2009).

circumstances which results in manslaughter, killing on request or infanticide.⁶⁹ Where ‘assisted suicide’ is undertaken, the person committing suicide must be competent, but a penalty will be given to the ‘assistant’ only if the ‘motivation’ for assisting or inciting someone to commit suicide, is ‘for selfish reasons.’⁷⁰

In February, 2007, the Federal Supreme Court of Switzerland ruled that under certain conditions, people with serious mental illness, may be permitted to commit physician-assisted suicide.⁷¹ If a patient is without capacity due to mental illness and may not understand fully the consequences of requesting physician-assisted suicide, the voluntariness of the request could be in question.

1.5.2 The Netherlands.

On April 10, 2002, the Netherlands became the first European country to decriminalise euthanasia. For the purposes of “The Netherlands Act,” or the “Termination of Life on Request and Assisted Suicide (Review Procedures) Act,” euthanasia, defined as follows, may only take place at the explicit request of the patient, the voluntary nature of the patient’s request being crucial:

“the termination of life by a doctor at the patient’s request, with the aim of putting an end to unbearable suffering with no prospect of improvement. It includes suicide with the assistance of a doctor.”⁷²

⁶⁹ Schwarzenegger, C., Summers, S. “Criminal Law and Assisted Suicide in Switzerland: Hearing with The Select Committee on The Assisted Dying For The Terminally Ill Bill, House of Lords.” [Online] (2005), Article 111.

⁷⁰ Ibid., Article 115; Civil Code, Article 16.

⁷¹ Paperchase Newsbust. “Swiss Court Extends Physician-Assisted Suicide to Incurable Mental Patients.” *Jurist: Legal News and Research* [Online] (2007).

⁷² Ministry of Health, Welfare and Sport and The Ministry of Justice. “Euthanasia The Netherlands’s New Rules: The Termination of Life on Request and Assisted Suicide (Review Procedures) Act” [Online] (2002).

Also included in the definition as ‘not’ being euthanasia, is the withdrawing or withholding of medical treatment, or where a doctor decides against treatment that would be futile, or where a doctor administers pain-relieving medication with the side effect of hastening death.⁷³

In this definition, euthanasia is defined as being restricted to where it is administered by a doctor and could also be interpreted as the only treatment for unbearable suffering. This could encourage clinicians to focus on terminating the patient’s life rather than administering appropriate life-saving treatments.

1.5.3 Belgium

“The Belgian Act on Euthanasia of May, 28th, 2002” is also limited to euthanasia that is voluntary.⁷⁴ Similar to the Netherlands Act, for the purposes of the Act, euthanasia is defined as:

“intentionally terminating life by someone other than the person concerned, at the latter’s request.”⁷⁵

This definition is not restrictive to euthanasia being administered only by a doctor. Included in the guidelines are the conditions and procedure for the termination of life, that the patient should be legally conscious when making the request which should be “well-considered and repeated and is not the result of any external pressure,” that s/he be of legal age, legally competent, in a medically futile condition, suffering unbearable physical or mental pain which cannot be alleviated, caused by an illness or accident.⁷⁶

⁷³ Ibid.

⁷⁴ Kidd, D. tr., Nys, H., tr. “The Belgian Act on Euthanasia of May, 28th 2002,” Ethical Perspectives [Online] (2002) 9 (2-3). [This unofficial translation was provided by Dale Kidd under the supervision of Prof. Herman Nys, Centre for Biomedical Ethics and Law, Catholic University of Leuven, Belgium.].

⁷⁵ Ibid.

⁷⁶ Ibid.

However, the terms “well-considered” and “repeated” are vague with no indication how often the request be repeated and to whom and it is unclear how patients in a medically futile condition who are experiencing physical or mental pain could make a rational decision.

1.5.4 Luxembourg

The legalisation of euthanasia came into force in Luxembourg on 1st April, 2009 and in June, 2009, the “Guide des soins palliatifs” was publicised, explaining to those patients in the advanced stages of terminal illness, or with serious/incurable disease, the new laws relating to palliative care and end-of-life care and support, including on request the provision of a substance to end life.⁷⁷

The Luxembourg definition is limited to euthanasia that is voluntary. Nurses could have new responsibilities when caring for the dying patient to include provision of a substance to end the patient’s life.

1.6 Definitions of Euthanasia in The United States of America

At present, two states in the United States have decriminalised assisted suicide: Oregon and Washington. The Washington and Oregon “Death with Dignity Acts” are very similar. Both definitions refer to the voluntariness of the act and to the competence of the person seeking assistance to end his/her life.

⁷⁷ Portail Santé, Grand-Duché de Luxembourg. Guide des Soins Palliatifs [Online] (2009). [[Translated from French to English, and used by permission of Brigitte Melsunt, translator.]

1.6.1 State of Oregon

With the introduction of the “Oregon Death with Dignity Act” on October 27, 1997, ‘assisted suicide’ became a ‘medical treatment’ if the assistance is provided by a physician.⁷⁸ Only those who have been approved by a doctor, are suffering from a terminal illness and who voluntarily express a wish to die can be provided medication for the purpose of ending his/her life in a “humane and dignified manner.”⁷⁹

1.6.2 Washington State

The “Washington Death with Dignity Act” (Initiative Measure No. 1000) passed on November 4, 2008, and enacted on March 5, 2009, also determines that ‘assisted suicide’ is a ‘medical treatment’ if the assistance is provided by a physician and for the purpose of ending his or her life in a “humane and dignified manner.”⁸⁰ The patient should be suffering from a terminal disease, able to make a written request, ABLE TO self-administer, and have voluntarily expressed a wish to die.

As well as both definitions referring to the requirement that the request is voluntary and that a physician provides assistance, they also refer to the patient’s life being ended in a “humane and dignified manner.” However, it is not clear how that is to be achieved if the patient is suffering from a terminal disease which may impede his/her ability to self-administer effectively.

⁷⁸ State of Oregon. “State of Oregon Death with Dignity Act - Legislative Statute.” [Online] (1997).

⁷⁹ Ibid.

⁸⁰ Washington State Department of Health. “Washington State Death with Dignity Act, Initiative 1000” [Online] (2008).

1.6.3 Euthanasia in The State of Montana

“Baxter v. State of Montana (Case No. DA 09-0051).”⁸¹ On December 31, 2009, the Montana Supreme Court ruled that state law does not prevent physicians from assisting patients in killing themselves.⁸² The Court decided that Montana had no statutory prohibitions on assisted suicide and that doctors could be shielded from prosecution for prescribing lethal doses to patients wanting to die.⁸³

1.7 Definitions of Euthanasia from a Secular Perspective.

The following definitions of euthanasia are offered by philosophers in the field of bioethics, writing from a secular perspective. Some authors argue for a narrow definition, effectively limiting euthanasia to what is active and voluntary, and others defend a much broader definition; hence this section is divided into those authors who offer definitions that are ‘narrow’ or ‘broad.’

1.7.1 A Narrow Definition of Euthanasia

1.7.1.1 Peter Singer

In the field of applied ethics, Peter Singer represents one of the most radical approaches to life and death issues in the contemporary world, given his rejection of treating human beings as a favoured species.⁸⁴ He regards ‘assisted suicide’ and ‘voluntary euthanasia’ as being similar, both being decisions made by autonomous beings.⁸⁵ His view is that,

⁸¹ Comparative Constitutions. “Dignity, Death and The Depth of Comparative Engagement in The US,” ComparativeConstitutions.org [Online] (2009); Family Research Council. “Legal Brief – In The Supreme Court of The State of Montana: Case DA09-0051” Family Research Council [Online] (2009).

⁸² State Law Library of Montana. “Montana Supreme Court Cases: Baxter v. State (DA 09-0051” [Online] (2009).

⁸³ Ibid.

⁸⁴ Singer, P. Practical Ethics, 2nd ed., (Cambridge University Press, Cambridge, 1993) vii.

⁸⁵ Ibid., 176.

there is no moral difference between killing (active euthanasia) and allowing to die (passive euthanasia).⁸⁶

He defines euthanasia that is 'active' as 'voluntary,' claiming that even if a person is not able to indicate that he has a wish to die, but may have written an advanced directive, right up to the moment when someone kills him, it is still 'voluntary' euthanasia.⁸⁷

Singer does not view euthanasia as being 'involuntary' or 'non-voluntary,' but merely a justification of ending a life that has no value and preventing the being from suffering in the future.⁸⁸ Singer's definition of euthanasia requires that clinicians make quality of life judgments on the value of a person's life.

1.7.2 A Broad Definition of Euthanasia

1.7.2.1 Beauchamp and Childress

Beauchamp and Childress's "Principles of Biomedical Ethics" is used as a standard text in many parts of the United Kingdom and of the United States, where medical ethics is taught to doctors or nurses.⁸⁹ 'Assisted suicide' and 'voluntary active euthanasia' are defined as being instances of 'assistance' in bringing about the person's death. Euthanasia that is 'involuntary' is where the person opposes being killed and 'non-voluntary' where the person is incapable of making an informed request.⁹⁰

According to them, mercy killing and assisted suicide is justified in some individual cases where the patient is suffering from extreme pain and 'physician assisted suicide'

⁸⁶ Ibid., 176, 178.

⁸⁷ Ibid., 207, 209.

⁸⁸ Ibid., 179-180; 181.

⁸⁹ Beauchamp, T., Childress, J. Principles of Biomedical Ethics, 6th ed., (Oxford University Press, New York, Oxford, 2009).

⁹⁰ Ibid. 228. 230.

should be part of the responsibility of caring for the patient, although never obligatory.⁹¹ Their view is that “medically administered nutrition and hydration” can be removed legitimately, paving the way for death, especially for those who are considered to be in a persistent vegetative state or suffering from dementia.⁹²

1.7.2.2 H. Tristram Engelhardt

Engelhardt’s emphasis upon autonomy and responsibility, in a pluralist society seeking to live in peace and tolerance, makes his philosophy attractive in modern Western societies, where his ideas are often used in medical ethics courses.⁹³

Engelhardt’s view is that, there are often competing interests between the principles of ‘beneficence’ and ‘autonomy,’ but that respect for the freedom of others and their choice of ‘passive’ euthanasia is often more easily justified than duties of beneficence and restrictions on ‘active’ euthanasia.⁹⁴ In his opinion, any physician-patient agreement or contract which has been established through a beneficent relationship could include euthanasia that is ‘passive’ as well as ‘active,’ since he condones the hastening of death, claiming that it may be in the patient’s interest.⁹⁵

1.7.2.3 John Harris

In his exploration of the principal ethical dilemmas that arise in medical practice and research, Harris defines euthanasia that is ‘voluntary’ as occurring where the patient does not make the initial request, but the decision “coincides” with the patient’s own

⁹¹ Ibid., 228, 241.

⁹² Ibid., 206.

⁹³ Engelhardt, H.T. The Foundations of Bioethics (Oxford University Press, Inc. New York, 1986).

⁹⁴ Ibid., 248-249.

⁹⁵ Ibid., 248-249; 316.

wishes, who then consciously approves of it and all aspects of its implementation.⁹⁶ In euthanasia that is 'involuntary' and 'non-voluntary' the decision is also made first by someone other than the patient.⁹⁷ Harris does not consider voluntary euthanasia or suicide to be morally wrong; that there are some situations where non-voluntary euthanasia is acceptable and involuntary euthanasia, although wrong, may be justifiable.⁹⁸

Harris defines euthanasia that is 'passive' in terms of the selective treatment of severely handicapped children where decisions are made to withhold treatment, that is, not to give antibiotics for infections, or food, or remedial surgery, knowing that by doing so, the child will die as a result and believing that the child will be better off dead.⁹⁹ He comments that passive euthanasia is viewed by some as a "negative responsibility" which is somehow considered to be morally preferable to the "positive responsibility" in active euthanasia.¹⁰⁰

1.8 Definitions of Euthanasia from a Christian Perspective

To meet the aim of this study, the meaning of euthanasia is explored from a Christian perspective in relation to healthcare ethics and bioethics. In the context of Christian tradition, the term 'innocent' separates the deliberate killing of a human being who has committed a crime and where a sentence of the death penalty is imposed, from those who have not committed a crime.¹⁰¹ This section is divided into those authors who offer

⁹⁶ Harris, J. *The Value of Life: An Introduction to Medical Ethics* (Routledge & Kegan Paul, London, 1985) 82-83; 261. [John Harris, Professor of Applied Philosophy, University of Manchester, England.].

⁹⁷ *Ibid.*, 82-83.

⁹⁸ *Ibid.*, 83.

⁹⁹ *Ibid.* 33-34.

¹⁰⁰ *Ibid.*, 33.

¹⁰¹ CCC n. 2267.

a 'narrow' or 'broad' definition of euthanasia and those whose definition is closer to or based upon that of the Magisterium.

1.8.1 A Narrow Definition of Euthanasia

1.8.1.1 F. J. Fitzpatrick

In examining how the principles of ethics are applied to complex ethical issues in nursing practice, Fitzpatrick defines euthanasia as, being the deliberate killing, or 'direct killing' of an 'innocent' human being in order to spare him/her from suffering and whose life is judged either by him/her self, or by others to have no value.¹⁰² Fitzpatrick focuses on euthanasia as being 'voluntary' and occurring when the person, whose life is being ended, consents to being killed.¹⁰³ He states that those who defend only voluntary euthanasia would not defend or promote involuntary euthanasia, where the killing is performed without the consent of the patient.¹⁰⁴

Fitzpatrick accepts there are difficulties in determining the intentions of those who make quality of life judgments to discontinue treatment which is considered futile, but where the patient may not necessarily be dying.¹⁰⁵ He considers the distinction that other writers make between 'active euthanasia' and 'passive euthanasia' to be a confusing piece of terminology.¹⁰⁶

¹⁰² Fitzpatrick, F. Ethics in Nursing Practice (The Linacre Centre for Health Care Ethics, London, 1988). 190, 191, 198.

¹⁰³ Ibid., 186, 188.

¹⁰⁴ Ibid. 186.

¹⁰⁵ Ibid. 190.

¹⁰⁶ Ibid. 200.

1.8.2 A Broad Definition of Euthanasia

1.8.2.1 James F. Keenan

Keenan examines the ‘moral’ distinction between ‘killing and letting die’ in the context of whether a medical professional may, or should, help end the life of a terminally ill patient at his/her request.¹⁰⁷ He distinguishes between what is morally prohibited, as in the “direct killing of innocents” and the morally ambiguous, where it is necessary to morally review whether a particular omission in letting die is licit.¹⁰⁸ For example, the removal of hydration and nutrition (by artificial means) does not mean that it is morally licit, but that it is “subject to moral evaluation” to determine whether it could be considered as extraordinary treatment, a morally right or a morally wrong instance of letting die.¹⁰⁹ According to him, although there is a physical difference between ‘withholding’ and ‘withdrawing’ treatment, which includes the removal of hydration and nutrition by artificial means, there is no moral difference.¹¹⁰

1.8.2.2 Kevin T. Kelly

In examining an ‘experienced-based’ moral theology as applied to the different challenges of everyday Christian life, Kelly focuses on the dignity of the human person, violation of which should be prevented.¹¹¹ His view is that human life is not necessary an absolute value to be defended at all costs in the absence of other dimensions of

¹⁰⁷ Keenan, J. “Assisted Suicide and The Distinction Between Killing and Letting Die.” Catholic Medical Quarterly [Online] (May 1992). [James Keenan, S.J., Jesuit, New York Province since 1970, Professor in Theology, Boston College, Massachusetts, USA].

¹⁰⁸ Ibid.

¹⁰⁹ Ibid.

¹¹⁰ Ibid.

¹¹¹ Kelly, K. New Directions in Moral Theology (Geoffrey Chapman, London, 1992) 21. [Reverend Kevin T. Kelly, Priest, inner-city parish, Liverpool].

human good.¹¹² Kelly does not justify the person being “kept alive at any cost,” stating that:

“To fight against the normal human dying process when the quality of life has become virtually sub-human is to mistake the place of physical life as a dimension of the good of the human person.”¹¹³

Kelly states that the view taken by the Council of Fathers in ‘Gaudium et spes’ (n.27), is not in conflict with the current dialogue in contemporary society, that whatever is opposed to life, including euthanasia and wilful self-destruction, violates the integrity of the human being.¹¹⁴ This would suggest that Kelly has a broader concept of euthanasia.

1.8.2.3 John Mahoney

Mahoney explores ‘death and dying’ through the complexities involved with religious belief and medicine.¹¹⁵ He examines the human ‘right to die’ as a claim to a moral entitlement and states that there are two ways of regarding this right.¹¹⁶ The first, that a person be “allowed or permitted to die,” understood as a right not to be prevented from dying once the dying process has begun and that no extraordinary measure be undertaken to keep the person alive; the second, that the person has a right to take his own life, understood as receiving assistance, only where the other person agrees to co-operate with assisted suicide or euthanasia.¹¹⁷ He defines euthanasia as “mercy-killing” that is, “putting to death from a motive of mercy.”¹¹⁸

¹¹² Ibid., 42.

¹¹³ Ibid., 42.

¹¹⁴ Ibid., 21.

¹¹⁵ Mahoney, J. *Bioethics and Belief* (Christian Classics, Inc., Maryland, USA, 1984) 36–47. [John (Jack) Mahoney, S.J., former Principal of Heythrop College, University of London].

¹¹⁶ Mahoney, J. “On a Human Right to Die” in, Clague, J., Hoose, B., Mannion, G., eds., *Moral Theology for The Twenty-First Century: Essays in Celebration of Kevin Kelly* (T & T Clark, London, 2008) 106–112.

¹¹⁷ Ibid., at 106, 107.

¹¹⁸ Ibid., at 106.

Mahoney defines euthanasia that is 'voluntary' where the person requests the administration of such, either at the time or, "in anticipation," of such a time, although he acknowledges this could be motivated by the person's depression or fear of being a burden on others.¹¹⁹ He also suggests that, if euthanasia is considered as a benefit to the patient, it should not, therefore, be limited to those requesting it however, the acceptance of euthanasia that is 'involuntary' could pressurise others to administer it.¹²⁰

1.8.2.4 Richard A. McCormick

McCormick analyses the ethical problem of 'killing and letting die' encountered by those in the medical profession.¹²¹ Where a person is being allowed to die, McCormick suggests the process could be hastened by active intervention.¹²² In his opinion, it is acceptable to make qualitative judgments about human life, but there is a responsibility to ensure the right criteria for these judgments, for example in asserting the difference between 'ordinary means' (those means whose use does not entail grave hardships to the patient) and 'extraordinary means' (those means that would involve such hardship).¹²³ Central to his definition of "direct" and "indirect" killing of an innocent human person is the key element of "proportionate reason."¹²⁴

1.8.2.5 Charles E. Curran

Curran examines death and dying from a theological perspective where the dignity and worth of the human is based on the fact that life is a gift from God and this premise

¹¹⁹ Mahoney, J. Bioethics and Belief (1984) 36-47 at 41.

¹²⁰ *Ibid.*, at 41.

¹²¹ McCormick, R. How Brave a New World: Dilemmas in Bioethics (SCM Press Ltd., London, 1981). [Richard A. McCormick, S.J.: Died on 12 February, 2000, at The Jesuit Infirmary, Colombiere Center, Detroit, Michigan.].

¹²² *Ibid.*, 23.

¹²³ *Ibid.*, 401, 344.

¹²⁴ *Ibid.*, 414. [Where a patient is faced with treatment that could endanger his/her life, there must be a proportionate reason, that is a reason that is sufficiently serious to justify the treatment which in itself must be objectively good. Consideration should also be given to the proportionate risk.].

provides the necessary foundation for defending the ‘equality’ of all human lives.¹²⁵ Although Curran points out that Catholic tradition has condemned ‘direct killing,’ he states that human life is not an absolute value since human life includes the legitimate right to kill an unjust aggressor in self-defence.¹²⁶ Therefore, the ethical theory that ‘direct killing,’ is always a wrong cannot be endorsed with confidence, since it is dependent on the limited knowledge and understanding of the human act.¹²⁷

According to him, since Catholic understanding is that one does not have to keep the person alive using means that are disproportionate to any expected results, the “life-death, good-evil oppositional approach” to euthanasia is too restrictive because it does not include the difference between withdrawing a means and interfering positively in order to bring about death.¹²⁸ Curran’s viewpoint is that the official Catholic hierarchical position that “the direct and voluntary killing of an innocent human being is always gravely immoral,” does not recognise the many nuances and has less certitude associated with euthanasia.¹²⁹ This would suggest that he has a broader concept of euthanasia.

1.8.2.6 Lisa S. Cahill

Cahill examines ‘direct euthanasia’ from a bioethical viewpoint stating that in Catholic tradition, the difference between a direct ‘action’ which causes death (killing) and the ‘withdrawal’ of burdensome technologies (allowing to die) is that although the human

¹²⁵ Curran, C.E. *Moral Theology: A Continuing Journey* (University of Notre Dame Press, Notre Dame-London, 1982) 103-104; 106-107. [Charles E. Curran, Elizabeth Scurlock University Professor of Human Values, Southern Methodist University, Dallas.]

¹²⁶ Curran, C. “Evangelium Vitae and Its Broader Context” in Curran, C., McCormick, A., eds. *John Paul II and Moral Theology: Readings in Moral Theology, Series No. 10* (Paulist Press, New York, 1998) 120-133 at 124.

¹²⁷ *Ibid.*, at 124.

¹²⁸ *Ibid.*, at 125.

¹²⁹ *Ibid.*, at 124-125.

involvement is significantly different, both actions bring the same result.¹³⁰ She states that, the moral difference in causing death depends on ‘direct intention’ being a choice of death in itself for its own sake and ‘indirect intention’ being, for example, the withdrawal of burdensome technologies or choosing pain-killers with a side-effect of hastening death.¹³¹

Cahill rejects ‘autonomy’ as an insufficient moral guide on which to conclude that death is preferable to continued life, seeking more objective criteria based on the physical suffering of the patient.”¹³² Not included in this definition as euthanasia, is the ‘withholding’ of treatment. Nor is it clear if ‘burdensome technologies’ includes nutrition and hydration administered artificially.

1.8.3 Those Authors Whose Definition is Closer To or Based Upon That of The Magisterium.

1.8.3.1 Luke Gormally

Within the context of clinical practice and the law, Gormally describes ‘voluntary euthanasia’ as “killing of the patient at his or her request” in the belief that, since death is considered to be a benefit, the killing is justified.¹³³ Those assisting in suicide have determined that the person intending to kill himself would benefit from being dead.¹³⁴

¹³⁰ Cahill, L. “Notes on Moral Theology: Bioethical Decisions to End Life.” Theological Studies (1991) 52, 107-127 at 120, 121. [Lisa Sowle Cahill, J. Donald Monan Professor, Theology Department, Boston College Massachusetts].

¹³¹ Ibid., at 121.

¹³² Ibid., at 124.

¹³³ Gormally, L. “Euthanasia and Assisted Suicide: Seven Reasons Why They Should Not be Legalised.” (The Linacre Centre for Health Care Ethics, London, 1997) [Online].

¹³⁴ Ibid.

Gormally defines euthanasia as a positive act and also occurring where a planned course of omissions may be carried out to terminate someone's life.¹³⁵ This includes omitting to provide adequate nutrition in order to starve the patient.¹³⁶

He emphasises the need to provide quality care and substantive palliative care and states that, by doing so, this provides an alternative to doctors and nurses to the temptation to dispose of some of their patients.¹³⁷

1.8.3.2 Helen Watt

Similar to Gormally, in examining the moral issues within healthcare ethics, Watt defines euthanasia as:

“the intentional shortening of life, by act or omission, on the grounds that it is not worth living...”¹³⁸

Included in her definition of euthanasia is that it can be ‘active’ or ‘passive,’ ‘voluntary,’ ‘non-voluntary,’ or ‘involuntary’ and that this is dependent on whether the patient has consented and on the methods used.¹³⁹ Her view is that, although patients have a right to autonomy which needs to be respected, those rights do not include involving doctors in complicity with suicide.¹⁴⁰

¹³⁵ Gormally, L. “The BMA Report on Euthanasia and The Case Against Legalization” in Gormally, L., ed., Euthanasia, Clinical Practice and The Law (The Linacre Centre for Health care Ethics, London, 1994) 185, 187.

¹³⁶ *Ibid.*, 187.

¹³⁷ *Ibid.*, 187.

¹³⁸ Watt, H. “Euthanasia: Unpacking the Debate” (The Linacre Centre for Healthcare Ethics, London, 2002) [Online].

¹³⁹ Watt, H. Life and Death in Healthcare Ethics (Routledge, Taylor & Francis Group, London, 2000) 27-28; 77.

¹⁴⁰ Watt, H. “The Case Against Assisted Dying” (The Linacre Centre for Healthcare Ethics) [Online] (2008).

1.8.3.3 Benedict M. Ashley, Jean Deblois, Kevin D. O'Rourke

In their theological analysis of health care ethics, Ashley, Deblois and O'Rourke acknowledge that 'euthanasia' has many definitions which also include the terms 'active' and 'passive' but their preferred definition is that as given by the Congregation for the Doctrine of the Faith:

“By **euthanasia** is understood an action or omission of an action which of itself or by intention causes death in order that all suffering may be eliminated....”¹⁴¹

They explain that, if it is performed by an omission which does not have this purpose, the action is not euthanasia.¹⁴²

'Assisted suicide' is defined as formal co-operation with the intentional destruction of another's bodily life.¹⁴³ Where physicians assist with the suicide, they prescribe the lethal medication to enable the person to carry out the action.¹⁴⁴ Their view is that the provision of palliative care and the ability to control pain supersedes the requirement for physician-assisted suicide.¹⁴⁵

1.8.3.4 Germain Grisez

In discussing the Christian life, Grisez states that people seldom wish to be killed, nor wish any member of their family to be killed.¹⁴⁶ According to him, 'suicide' (a person's intentional killing of him/herself) 'assisted suicide' and 'euthanasia,' are all ways of killing 'innocent' persons intentionally, involving the same type of moral act and he states:

¹⁴¹ Ashley, B., Deblois, J., O'Rourke, K. Health Care Ethics: A Theological Analysis, 5th ed., (Georgetown University Press, Washington, 2006) 180.

¹⁴² Ibid., 180.

¹⁴³ Ibid., 178.

¹⁴⁴ Ibid., 179.

¹⁴⁵ Ibid., 179

¹⁴⁶ Grisez, G. The Way of The Lord Jesus, Vol. 2, Living A Christian Life (1993) 469.

“To will death as an end or as a means is to intend to kill ...*Intend* sometimes refers exclusively to the willing of an end, as distinct from the choice of a means, but sometimes it refers both to the willing of an end and the choice of a means, as distinct from accepting foreseen side effects.”¹⁴⁷

Grisez defines the term, ‘means’ as being “some performance or omission.”¹⁴⁸

1.8.3.4 William E. May

In discussing Catholic bioethics, May fundamentally agrees with Grisez in that all intentional killing of an ‘innocent’ person is morally the same.¹⁴⁹ He defines euthanasia as being ‘active’ (direct or positive euthanasia) where a person is killed intentionally by an ‘act of commission’ either voluntarily if consent is given, or non-voluntarily or involuntarily.¹⁵⁰ ‘Passive’ euthanasia (indirect or negative euthanasia) occurs by an ‘act of omission’ such as the withholding or withdrawing of treatments precisely as a way of bringing about the person’s death.¹⁵¹ It can be voluntary, non-voluntary or involuntary. ‘Assisted suicide’ is where a person formally co-operates in the “killing act,” but where the patient is the principal cause of the killing.¹⁵²

1.9 Definitions of Euthanasia as Used in Magisterial Texts

For the purpose of the study, the researcher has selected four Magisterial sources, the first three of which are in Catholic moral theology. ‘Magisterium’ means the official teaching authority of the Catholic Church on matters of faith and of morals.¹⁵³ It is that

¹⁴⁷ Ibid., 470, 471, 477, 480.

¹⁴⁸ Ibid., 471.

¹⁴⁹ May, W. *Catholic Bioethics and The Gift of Human Life*, 2nd ed. (Our Sunday Visitor Publishing Division, Our Sunday Visitor, Inc. Huntingdon, Indiana, 2008) 261.

¹⁵⁰ Ibid., 262.

¹⁵¹ Ibid., 262.

¹⁵² Ibid., 263.

¹⁵³ O’Collins, G., Farrugia, E., *A Concise Dictionary of Theology* (Rev. ed.) (T & T Clark, Edinburgh, 2000) 148.

given by the Pope or, by an ecumenical council in union with the Pope and being authoritative for the Catholic Church throughout the world, as is such teaching by the Congregation for the Doctrine of the Faith when approved by the Pope (although it is at a lower level) and that of diocesan bishops, provided it is compatible with the former.

In what follows, the Papal encyclical or teaching document, ‘*Evangelium vitae*,’ is the highest level of teaching addressing euthanasia, because it is given by the Pope as a teaching document, although the ‘*Catechism of the Catholic Church*’ gives a summary of relevant doctrine. Chronologically first and in fact most extensive in its treatment of this matter is the declaration ‘*Jura et bona*.’

1.9.1 *Jura et bona*

The Sacred Congregation for the Doctrine of the Faith refers to euthanasia as some “intervention of medicine” and is understood as being the intentional killing of an ‘innocent’ human being who is considered to have no quality of life, such as “abnormal babies, the mentally ill, or the incurably sick,” and is defined as:

“an action or an omission which of itself or by intention causes death, in order that all suffering may in this way be eliminated.

Euthanasia’s terms of reference therefore are to be found in the intention of the will and in the methods used.”¹⁵⁴

It is administered, in order to end their extreme suffering, or spare them a lengthy miserable life or to relieve society and their families, of what is perceived as being a heavy burden.¹⁵⁵

¹⁵⁴ *Jura et bona*, 512.

¹⁵⁵ *Ibid.*, 512.

1.9.2 Evangelium vitae

In an encyclical letter on the value and inviolability of human life, John Paul II's definition of euthanasia is that of 'Jura et bona', but adds the distinction that the decision to forego "aggressive medical treatment" that is disproportionate to any expected result or no longer corresponds to the patient's real situation, or is a burden to the patient and/or his family, is not euthanasia.¹⁵⁶

1.9.3 Catechism of The Catholic Church

The Catechism of the Catholic Church's definition of euthanasia is that of 'Jura et bona.'¹⁵⁷ However, it refers to 'direct' euthanasia, the intentional ending of a person's life, as 'murder,' even for the purposes of eliminating suffering.¹⁵⁸ As in 'Evangelium vitae,' the definition includes as being legitimate, and so not euthanasia, the discontinuation of medical procedures that are disproportionate to their expected outcome where the intention is not to cause the patient's death, only to accept one's inability to impede it.¹⁵⁹

Reference is also made to the legitimate use of painkillers at the end of life, where the intention is to relieve suffering, not to hasten death, but with the foreseen risk that this may shorten the patient's life; this is not euthanasia.¹⁶⁰

1.9.4 United States Catholic Bishops' Conference.

The United States Catholic Bishops' Conference states, that legislation should always pre-suppose the right to life of every human being and should reflect the patient's moral

¹⁵⁶ Evangelium vitae, n.64.

¹⁵⁷ CCC, n. 2277.

¹⁵⁸ CCC, n. 2277.

¹⁵⁹ CCC, n. 2278.

¹⁶⁰ CCC, n. 2279.

responsibility for requesting reasonable treatment, his right to refuse treatment, as well as recognising the presumption of ordinary care such as hydration and nourishment.¹⁶¹

According to them:

“euthanasia includes not only active mercy killing but also the omission of treatment when the purpose of the omission is to kill the patient.”¹⁶²

Where the patient faces imminent death, provision of artificial hydration and nutrition may be disproportionately burdensome to him and is not morally obligatory; however, this should not be withdrawn with the intention to cause the patient’s death, since a deliberate omission of such, is an act of euthanasia.¹⁶³

In August, 2007, this position was further confirmed and clarified to the United States Conference of Catholic Bishops by the Congregation for the Doctrine of the Faith, that it is morally obligatory to administer food and water, including by artificial means, “in principle” to a patient in a “vegetative state,” considered not to be a terminal illness, but where the patient is unable to feed himself.¹⁶⁴ If those patients do not receive such ordinary and proportionate care, their deaths will be due to starvation and dehydration, not of any medical condition.¹⁶⁵ The Congregation acknowledges that there will be

¹⁶¹ United States National Conference of Catholic Bishops’ Committee for Pro-Life Activities, “Guidelines for Legislation on Life-Sustaining Treatment” (10 November 1984), *Origins* 14: no. 32, Jan. 24, 1985, pp. 526-528 in O’Rourke, K., Boyle, P. Medical Ethics: Source of Catholic Teachings, 3rd ed, (Georgetown University Press, Washington, 1999) 241-243 at 243.

¹⁶² United States National Conference of Catholic Bishops’ Committee for Pro-Life Activities, “Nutrition and Hydration: Moral and Pastoral Reflections,” *Origins* 21: no. 44 (April 9, 1992) pp. 705-12 in, O’Rourke, K., Boyle, P. Medical Ethics: Source of Catholic Teachings, 3rd ed, (Georgetown University Press, Washington, 1999) 215-219 at 216.

¹⁶³ *Ibid.* at 216.

¹⁶⁴ Congregation for The Doctrine of The Faith. Responses to Certain Questions of The United States Conference of Catholic Bishops Concerning Artificial Nutrition and Hydration [Online] (2007).; Congregation for The Doctrine of The Faith. Commentary: Responses to Certain Questions of The United States Conference of Catholic Bishops Concerning Artificial Nutrition and Hydration [Online] (2007).

¹⁶⁵ Congregation for The Doctrine of The Faith. Responses to Certain Questions of The United States Conference of Catholic Bishops Concerning Artificial Nutrition and Hydration [Online] (2007).

some situations where it would be impossible to access the means to provide artificial hydration and nutrition.¹⁶⁶

1.9.5 Catholic Bishops' Conference of England and Wales

The Catholic Bishops' Conference of England and Wales reject the promotion or encouragement of suicide as well as euthanasia, which involves the 'intentional' killing of another person even where that person may have requested it.¹⁶⁷ They define 'passive euthanasia' as the withdrawal of nutrition by artificial means and other life-sustaining treatment in order that the patient dies.¹⁶⁸ They state that giving high doses of painkillers, even at the risk of shortening life may be necessary, but, if this is used as a means to euthanasia, it is not acceptable.¹⁶⁹

In May, 2009, prior to "The Coroners and Justice Bill: Amendment 173 [2009]" being debated, the Most Reverend Peter Smith, then Archbishop of Cardiff, commented that the issues surrounding legalisation of assisted suicide were contradictory, since it would entail banning encouragement of suicide but allow assistance with it.¹⁷⁰ On July 31, 2009, he commented on "The Law Lords' decision requiring the Director of Public Prosecutions to publish an offence-specific policy statement clarifying the law on assisted suicide," stating that no-one should feel compelled to seek assistance in suicide.¹⁷¹

¹⁶⁶ Congregation for The Doctrine of The Faith. Commentary: Responses to Certain Questions of The United States Conference of Catholic Bishops Concerning Artificial Nutrition and Hydration [Online] (2007).

¹⁶⁷ Catholic Bishops' Conference of England and Wales. Cherishing Life (The Catholic Truth Society and Colloquium (CaTEW) Ltd., London, 2004) nn. 180-187 at 183.

¹⁶⁸ Ibid. 185.

¹⁶⁹ Ibid. 187.

¹⁷⁰ Catholic Communications Network. "Comment by Archbishop Peter Smith on Assisted Suicide Amendments to The Coroners and Justice Bill" [Online] (2009). [Chairman of the Bishops' Conference Department of Christian Responsibility and Citizenship].

¹⁷¹ Catholic Communications Network. "Comment on The Debbie Purdy Judgment from Archbishop Smith." [Online] (2009).

In November, 2009, The Catholic Bishops' Conference of England and Wales published a detailed response to the "Interim Policy for Prosecutors in Respect of Cases of Assisted Suicide Issued by The Director of Public Prosecutions (DPP)," stating that the terminology should be changed so that "assisting" should be referred to as "aiding and abetting" suicide, to remove the connotation of "helpfulness and benevolence."¹⁷²

1.9.6 Catholic Bishops' Conference of Scotland

In 2005, the Catholic Bishops' Conference of Scotland declared that in the case of terminal illness, extraordinary means do not need to be used to stay alive, but euthanasia which is never permitted, is defined as,

"any act or omission which causes, or is intended to cause death, in order to remove a person from suffering."¹⁷³

Similar to the English Bishops' Conference, The Scottish Bishops' Conference make the same distinction that it is legitimate to use painkillers even at the risk of shortening life, but not as a means to euthanasia.¹⁷⁴ Their concern is that the introduction of voluntary euthanasia will inevitably lead to non-voluntary euthanasia of the most vulnerable in society.¹⁷⁵ This position remains the same in August, 2010.

¹⁷² Catholic Bishops' Conference of England and Wales. "Interim Policy for Prosecutors in Respect of Cases of Assisted Suicide Issued by The Director of Public Prosecutions (DPP): Response from The Catholic Bishops' Conference of England and Wales" (Catholic Trust for England and Wales, London, 2009) [Online].

¹⁷³ Catholic Bishops' Conference of Scotland. "Euthanasia" [Online] (2005).

¹⁷⁴ Ibid.

¹⁷⁵ Ibid.

1.10 Advisory Bodies to Bishops

1.10.1 Linacre Centre

In 1982, The Linacre Centre published a 'Working Party' report which focused on the ethics of euthanasia in the clinical situation.¹⁷⁶ Initially, The Working Party defined euthanasia as:

“There is euthanasia when the death of a human being is brought about on purpose as part of the medical care being given him.”¹⁷⁷

However, because euthanasia is often justified as being a benefit to the patient, or as a benefit to others, on the basis of the patient's future mental or physical condition or his quality of life, they expanded their definition as follows:

“in euthanasia a person's death is brought about on the ground that, because of his present or likely future mental condition and quality of life (and sometimes in consideration too of the quality of life of his family) it would be better for him (or at least no harm) if that person were dead.”¹⁷⁸

Since 'intention' is central to any action, 'The Working Party' stated that the term 'murder' could not, be explained simply as 'intentional killing,' since some killing is legitimate even though intentional, for example in capital punishment.¹⁷⁹ According to them, the term 'murder' is defined reasonably well as 'intentional killing of an 'innocent' person.'¹⁸⁰ However, even where there is no intention to kill, there may still be murder, for example, where there is a malicious act which results unintentionally in

¹⁷⁶ Gormally, L., ed. Euthanasia, Clinical Practice and The Law (The Linacre Centre, London, England, 1994) vii; 2. [The original Members of the Working Party (1978-1981) were chaired by Rev. J. Mahoney, SJ, MA, DD, Principal of Heythrop College, University of London and comprised an interdisciplinary group of sixteen people].

¹⁷⁷ Ibid., 11

¹⁷⁸ Ibid., 11.

¹⁷⁹ Ibid., 37.

¹⁸⁰ Ibid., 38.

the death of a person.¹⁸¹ Death as a result of negligence is usually termed ‘manslaughter.’¹⁸² They also explain that ‘intention’ and ‘foresight’ should be distinguished, since, for example, a surgeon undertaking an operation in high-risk surgery would not be referred to as a murderer if the patient died; therefore ‘intention’ and ‘foresight’ should only be related in connection with “gravely unlawful acts.”¹⁸³

Where the death of a patient is one not intended by the agent, but a side-effect, of, for example, pain-killing drugs; this can be legitimate at times under the principle of double effect. This does not mean that “so long as death is not what you intend, you can cause it with a clear conscience” merely that it states there is a ‘possibility’ that death may occur as a result of the legitimate purpose for the action.¹⁸⁴ Furthermore, it is possible to commit murder (morally speaking) by ‘omission’ where a clinician intentionally omits to provide the necessary treatment or care to keep the person alive; “doing nothing” does not relieve the person from the responsibility of causing death.¹⁸⁵

In 1991, The Linacre Centre prepared a submission to ‘The Select Committee of The House of Lords on Medical Ethics’.¹⁸⁶ The issues involved were in relation to the moral understanding of medical practice. First, they re-affirmed the principle of the sanctity of human life, which requires that one should never adopt any course of ‘action or omission,’ identified by, a) the chosen purpose in acting, and, b) the means which are

¹⁸¹ Ibid., 38.

¹⁸² Ibid., 39.

¹⁸³ Ibid., 39, 48.

¹⁸⁴ Ibid., 48.

¹⁸⁵ Ibid. 46.

¹⁸⁶ The Linacre Centre for Health Care Ethics, “Submission to The Select Committee of The House of Lords on Medical Ethics” (1993) in Gormally, L., ed. Euthanasia, Clinical Practice and The Law (The Linacre Centre, London, England, 1994) 112-165. [The document was prepared on behalf of the Centre by Luke Gormally, its Director, by Professor John Finnis, FBA, Professor of Law and Legal Philosophy, University of Oxford and Vice-Chairman of The Board of Governors of the Centre; by Dr. John Keown, Lecturer in Law, The University of Cambridge and a Governor of the Centre.].

chosen, to intentionally kill an innocent human being.¹⁸⁷ In addition, they state that, there is no moral significance between ‘killing’ and ‘letting die,’ because it is possible to let someone die for unacceptable reasons, such as a desire to hasten his death.¹⁸⁸

According to the submission, ‘voluntary euthanasia’ (a request from a patient that the doctor kill him/her) considered by some as a benefit to the patient, is not consistent with recognising the dignity and value of the person.¹⁸⁹ Neither is suicide defined as a choice to kill oneself by a positive course of action, e.g. taking a lethal substance, or by deliberately omitting life-sustaining care.¹⁹⁰ This does not mean that doctors have a duty to provide “inefficacious treatment,” since a patient in a terminal phase of dying will not benefit from that treatment unless it has palliative benefits.¹⁹¹ Furthermore, patients in a ‘persistent vegetative state’ should not be deprived of ordinary care, including nutrition and hydration by artificial means, since this is not regarded as ‘medical treatment,’ but an “ordinary function of nourishing the patient.”¹⁹²

The focus in both reports is the prohibition of intentionally killing patients by an action or omission. However, since some intentional killing is legitimate, the Working Party states that the term ‘murder’ can not be explained as intentional killing unless the person killed is ‘innocent.’ The 1991 Submission re-iterates the content of the Working Party Report, but introduces the terms, ‘voluntary’ to include euthanasia that is requested by a patient and ‘suicide’ as not consistent with the dignity and value of the

¹⁸⁷ Ibid., 119, 126.

¹⁸⁸ Ibid., 127.

¹⁸⁹ Ibid., 128-129.

¹⁹⁰ Ibid. 137.

¹⁹¹ Ibid., 138.

¹⁹² Ibid., 141-142.

person and affirms that ‘artificial nutrition and hydration’ are not medical treatments but considered to be ordinary care.

1.10.2 Catholic Bishops’ Joint Bioethics Committee [England and Wales, Scottish and Irish Bishops’ Conferences].

The Catholic Bishops’ Joint Bioethics Committee is a unique body, set up by the three Catholic Bishops’ Conferences covering the territory of the United Kingdom and the Republic of Ireland. The Committee acts as advisors to, and agents of, the Bishops’ Conferences in bioethical matters.”¹⁹³

1.10.2.1 The Bishops’ Conference of England and Wales and The Bishops’ Conference of Scotland.

The Linacre Centre was originally to advise the Bishops’ Conference of England and Wales. Informal contacts with the Scottish Bishops’ Conference and with the Irish Bishops’ Conference have developed over the years and that these have now been formalised in very recent years. The Linacre Centre sometimes gives advice nowadays to all three Conferences and sometimes through the Joint Bioethics Committee. For example the Linacre Centre submission in 1991 to ‘The Select Committee of The House of Lords on Medical Ethics’ in relation to the moral understanding of medical ethics (1.10.1) and the advice related to the “Response to the Draft Mental Incapacity Bill” in 2003, are examples of such co-operation.¹⁹⁴

¹⁹³ Catholic Bishops’ Joint Bioethics Committee [Online] (2010).

¹⁹⁴ The Linacre Centre for Health Care Ethics, “Submission to The Select Committee of The House of Lords on Medical Ethics” (1993) in Gormally, L., ed. *Euthanasia, Clinical Practice and The Law* (The Linacre Centre, London, England, 1994) 112-165; The Linacre Centre for Healthcare Ethics, “Response to The Draft Mental Incapacity Bill, A Joint Submission by The Catholic Bishops’ Conference of England and Wales and the Linacre Centre for Healthcare Ethics” [Online (2003)].

In the “Response to the Draft Mental Incapacity Bill” the Catholic Bishops Conference of England and Wales and the Linacre Centre expressed concern that there were ineffective safeguards against suicide and homicide by omission and that nothing had been done to ensure that life-sustaining measures could not be withheld from non-PVS patients with the aim of causing death.¹⁹⁵ Also considered unacceptable is the weakness in the definition of “best interests” where decisions relating to the health of the patient are dependent on his past “wishes or feelings.” Furthermore, the proposed scheme for proxy decision makers gave them power without accountability and they recommended at least a prescribed duty of care and accountability within the law. Furthermore, they considered that, by enforcing advance directives, there is a risk these could be made with inadequate information, especially in relation to an advance refusal of pain relief, hygienic care, or nutrition and hydration administered orally or artificially and they recommended that no advance directive or person should have the power to refuse such interventions.¹⁹⁶

1.10.2.2 Irish Catholic Bishops’ Committee for Bioethics [2002].¹⁹⁷

The original Irish bioethics committee published a document on end-of-life care in 2002.¹⁹⁸ In discussing the ethical and pastoral issues of concern, the Irish Bishops’ Committee for Bioethics define euthanasia that is ‘active’ as a decision to end

¹⁹⁵ The Linacre Centre for Healthcare Ethics, “Response to The Draft Mental Incapacity Bill, A Joint Submission by The Catholic Bishops’ Conference of England and Wales and the Linacre Centre for Healthcare Ethics” [Online] (2003).

¹⁹⁶ Ibid.

¹⁹⁷ Irish Catholic Bishops’ Consultative Group for Bioethics [Online] (2010). [“In 1996 the Irish Bishops established a Committee for Bioethics, chaired by Bishop Donal Murray. Their intention was that the committee would contribute to the development and understanding of an ethos, consistent with the values of the Gospel, in relation to issues of healthcare and bio-medical research. In 2007 the committee was replaced by a panel of consultants drawn from a variety of professional disciplines, including medicine, nursing, social work, the natural sciences, philosophy and theology.”].

¹⁹⁸ Irish Bishops’ Committee for Bioethics. “End-of-Life Care: Ethical and Pastoral Issues” [Online] (2002).

life by a deliberate action and ‘passive’ by withholding or withdrawing ordinary means of nutrition or treatment, with the intention of hastening death.¹⁹⁹ Euthanasia is described as being ‘voluntary’ where it is requested or agreed by the person when proposed by others, ‘involuntary’ where the agreement is not sought and ‘non-voluntary’ where the agreement cannot be indicated due to the person being non-competent.²⁰⁰

Assisted suicide is described as taking place where another person provides assistance, but the “suicident” commits the last act; this is different from voluntary euthanasia where the person other than the one who dies performs the last act.²⁰¹ Their view is that there is a link between physical pain and emotional distress which can impact on a person’s request for euthanasia or assisted suicide; therefore, issues of autonomy are of concern.

1.11 The Magisterium’s Definition of Euthanasia

Magisterium is the name given in Catholic theology to the office of teaching concerning faith and morals in the church. The office belongs to the Pope and the bishops and is exercised by them in various ways. For our purposes it is enough to note that one of the main ways in which a Pope exercises magisterium is by way of ‘encyclical letters’, of which ‘*Evangelium vitae*’ (1995) of John Paul II is an example of great importance for the present work.²⁰² In the exercise of magisterium a Pope may make use of the work of Congregation for the Doctrine of the Faith; in this thesis the ‘Declaration’ entitled ‘*Jura et bona*’ (1980) is a critically central example. Official teaching derived from all

¹⁹⁹ Ibid.

²⁰⁰ Ibid.

²⁰¹ Ibid.

²⁰² Encyclicals and other official documents are usually known by the words with which they begin, and this explains why the initial letter of the second (and any subsequent) word is rendered in lower case.

such sources is to be found also in the ‘Catechism of the Catholic Church’ (1997), of which use is also made here.

In Catholic teaching euthanasia, understood as the intentional killing of an ‘innocent’ human person for reasons of mercy, is defined more precisely as:

“an action or an omission which of itself or by intention causes death with the purpose of eliminating all suffering.”²⁰³

This definition relies on a number of concepts and distinctions familiar in Catholic moral theology, including some which have been the subject of discussion and debate in recent decades. It is not possible here to enter into these debates, but the following offers an approach which is careful and useful, even if not on all points one with which everyone must agree.

1.11.1 Direct Intention

‘Intentional killing’, that is the willing of an end *and* the choice of a means, is synonymous with ‘direct killing.’²⁰⁴ This is not the same as desiring death, an emotional response to suffering where death may be attractive, but where there is an absence of a willingness or intention to kill.²⁰⁵ Choosing to kill is choosing to do or omit something that leads to death.²⁰⁶ In making a choice, the person has adopted a proposal to do something. The ‘doing’ carries out the choice whether by an action or an omission. This

²⁰³ Evangelium vitae, n. 65.

²⁰⁴ Grisez, G. The Way of The Lord Jesus Vol. 2. Living a Christian Life (Franciscan Press, Illinois, 1993) 470.

²⁰⁵ *Ibid.*, 470.

²⁰⁶ *Ibid.*, 472, 474.

means the person intends the end by choosing a means, either an action or omission likely to bring about the desired end.²⁰⁷

In addition to the specific intention of the act, the clinician may have some additional and special motive or “accidental circumstantial intention.”²⁰⁸ For example, a surgeon may perform a legitimate surgical operation with the specific intention of healing the patient, but the motive may be to make money.²⁰⁹ Therefore, in making a choice to end the life of a patient, the clinician may have a special motive, however, this is extrinsic to the action performed.

1.11.2 Indirect Intention

It is possible knowingly to cause death without intending it by doing something intentionally and causing something non-intentionally in bringing about a side effect; for example, administering pain relieving medication where one foresees and permits the possibility of hastening the person’s death, but has not caused it properly and directly.²¹⁰ The distinction lies in the willing of an end, that of death or relief from suffering, from the choice of a means, that of the deliberate choice of an act or an omission in order to cause the patient’s death, as distinct from accepting foreseen side effects.²¹¹

²⁰⁷ Ibid., 472.

²⁰⁸ Ashley, B., Debois, J., O’Rourke, K. Health Care Ethics: A Theological Analysis, 5th ed., (Georgetown University Press, Washington, U.S.A., 2006) 53.

²⁰⁹ Ibid., 53.

²¹⁰ Ibid., 471.

²¹¹ Grisez, G. The Way of The Lord Jesus, Vol. 2. Living a Christian Life (1993) 470.

1.11.3 An Action

Where the ‘intention’ is to relieve suffering, the person chooses an action, for example, to administer pain relieving medication. If the intention is to kill the patient, the person chooses to administer a lethal dose of pain-relieving medication and the outcome (the desired end) is immediate death.²¹² The act of itself would not be performed if this were not the intention of the clinician; therefore, there is a clear connection between the intention (intended goal or desired end) and the action.²¹³ Euthanasia, therefore, takes the form of being ‘active’ (direct or positive) where someone chooses intentionally to kill an ‘innocent’ person by an act of commission.²¹⁴

1.11.4 An Omission

A person can also choose intentionally to kill the patient by an omission. However, omissions do not actively cause death. For example, turning off a life-sustaining machine by itself does not cause death. Where a patient is temporarily on a respirator post surgical and when that respirator is eventually turned off, the patient usually goes on living. Where the patient dies, there is usually a prior acute pathological condition which causes the death.²¹⁵

Therefore, there must be a specific connection between the intention and the omission. If a clinician (doctor or nurse) can do something to sustain a patient’s life, but chooses to deliberately omit to do so in order that death will ensue, that omission (morally

²¹² Ibid., 471.

²¹³ Gómez-Lobo, A. “Quality of Life and Assisted Nutrition” in Tollefsen, C., ed., Artificial Nutrition and Hydration: The New Catholic Debate (Springer, The Netherlands, 2008) 103-110 at 107.

²¹⁴ May, W. Catholic Bioethics and The Gift of Human Life, 2nd ed. (Our Sunday Visitor Inc., Indiana, 2008) 262.

²¹⁵ Gómez-Lobo, A. “Quality of Life and Assisted Nutrition” in Tollefsen, C., ed., Artificial Nutrition and Hydration: The New Catholic Debate (2008) 103-110 at 107.

speaking) is a means of intentional killing.²¹⁶ An example would be choosing to omit to give life-saving medication, such as insulin, or choosing to give only water to a disabled new born baby and omitting to give nutrition, in order that the baby dies.²¹⁷

Therefore, euthanasia takes the form of being 'passive' (indirect or negative) when someone brings about the death of a person by an act of omission, that is withholding or withdrawing medical treatments that could preserve life in order to bring about the death of the patient.²¹⁸

1.11.5 Ordinary Means

A person is not always obliged to use all possible means to preserve and prolong human life. 'Ordinary' or 'proportionate' means are those which one is morally obliged to use in order to respect the dignity of the human life and to act as steward of that life. 'Ordinary' means takes into consideration the type of treatment to be used, its degree of complexity or risk, its cost, the possibilities of using it and this is then compared with the result that can be expected, taking into account the state of the sick person and his or her physical and moral resources.²¹⁹ 'Ordinary' and 'proportionate' care is morally obligatory for both patient and clinician, and this includes nutrition and hydration, unless death is imminent and inevitable and the patient is no longer able to assimilate these.²²⁰

²¹⁶ Grisez, G. The Way of The Lord Jesus Vol. 2. Living a Christian Life (1993) 474.

²¹⁷ Ibid., 474.

²¹⁸ May, W. Catholic Bioethics and The Gift of Human Life, 2nd ed. (2008) 262.

²¹⁹ Jura et bona, 515.

²²⁰ John Paul II. Address of John Paul II to The Participants in The International Congress on "Life-Sustaining Treatments and Vegetative State: Scientific Advances and Ethical Dilemmas" (20 March 2004) [Online].

1.11.6 Extraordinary Means

‘Extraordinary’ and ‘disproportionate’ means are optional, the clinician having no duty to use these means, not even at the request of the patient.²²¹ The burdens imposed by these treatments are considered to exceed the benefits likely to result from their use.²²² For example, these might be experimental, risky, painful, or might be contrary to the patient’s religious belief, or these might make excessive demands on him/her, physically, psychologically or socially.²²³

Therefore, to forego “aggressive medical treatment” that is disproportionate to any expected result or no longer corresponds to the patient’s real situation is not euthanasia.²²⁴ In addition, it is legitimate to discontinue medical procedures that are disproportionate to their expected outcome where the intention is not to cause the patient’s death, only to accept one’s inability to impede it.²²⁵ Furthermore, the legitimate use of painkillers at the end of life, where the intention is to relieve suffering, not to hasten death, but with the foreseen risk that this may shorten the patient’s life is not euthanasia.²²⁶

1.11.7 Clinical Implications

Euthanasia brought about by an act of commission or omission is morally the same, since each is the intentional killing of an innocent human person for reasons of mercy.²²⁷

²²¹ Calipari, M. “The Principle of Ethical Adequacy in The use of Means of preserving Life: Between Therapeutic Excess and Abandonment of The Patient.” in Sgreccia, E., Laffitte, J., Alongside The Incurably Sick and Dying Person: Ethical and Practical Aspects (2009) 158-177 at 175-176.

²²² May, W. Catholic Bioethics and The Gift of Human Life, 2nd ed. (2008) 282.

²²³ Ibid., 283.

²²⁴ Evangelium vitae, n.65; Jura et bona 515-516;

²²⁵ Evangelium vitae, n. 65; CCC, n. 2278.

²²⁶ Evangelium vitae, n. 65; Jura et bona, 514; CCC, n. 2279.

²²⁷ May, W. Catholic Bioethics and The Gift of Human Life, 2nd ed. (2008) 263.

However, there is a possibility that these distinctions and their interpretation may give rise to problems in clinical practice, unless clinicians have a clear understanding of under-pinning principles and criteria for decision-making.

1.12 Conclusion: A Working Definition of Euthanasia

1.12.1 Euthanasia: A Broad Definition

Included in euthanasia as part of a broad definition, is 'passive' euthanasia as being an 'omission to act' whereby life sustaining treatments or nutrition and/or hydration are withheld or withdrawn with the primary intention of causing or hastening death.²²⁸

'Omitting to act' can involve several means. An example can be found in one eugenic approach to euthanasia where passive euthanasia was undertaken by 'starvation' in order to eliminate certain selected people such as the handicapped, the elderly and those who were considered "unworthy of life."²²⁹ This is similar to Harris's account that some clinicians consider it acceptable to "let nature take its course" in the treatment of "selected people, especially handicapped children," but which is calculated to result in their deaths.²³⁰ 'Omitting to act' in these situations means that antibiotics are not given for infections, or food is not provided, or remedial surgery is not given.²³¹

However, a definition of euthanasia that is so broad that the patient cannot withdraw or refuse extraordinary treatment legitimately, is excessive and indefensible.

²²⁸ Ashley, B., Debois, J., O'Rourke, K. Health Care Ethics: A Theological Analysis, 5th ed., (2006) 180. Weller, B., ed., Baillière's Nurses' Dictionary for Nurses and Health Care Workers, 25th ed., (2009) 144; Maclean, A. Briefcase on Medical Law (2001) 93; May, W. Catholic Bioethics and The Gift of Human Life, 2nd ed. (2008) 261; Irish Bishops' Committee for Bioethics. "End-of-Life Care: Ethical and Pastoral Issues" [Online] (2002)

²²⁹ Hoskins, S. "Nurses and National Socialism – A Moral Dilemma: One Historical Example of A Route to Euthanasia." Nursing Ethics (2005) 12 (1) 79-91.

²³⁰ Harris, J. The Value of Life: An Introduction to Medical Ethics (Routledge & Kegan Paul, London, 1985) 33, 38.

²³¹ *Ibid.*, 33.

1.12.2 Euthanasia: A Narrow Definition

‘Active’ euthanasia, a positive act that causes death, or a deliberate act with the intention to terminate life by the use of drugs or other direct methods, is defined as ‘voluntary euthanasia’ administered by a physician.²³² However, that would mean that no member of a family could ever commit euthanasia and killing someone for reasons that they are suffering would be excluded for no good reason. Whilst this may be convenient from a legal perspective, morally this is far too restrictive.

Even if not limited to administration by a doctor, a definition limiting euthanasia to that which is active and ‘voluntary’ such that as it would appear to suggest that ‘involuntary’ and ‘non-voluntary’ are not forms of euthanasia at all, is too narrow and therefore inadequate for this thesis.

1.12.3 The ‘Intention’ and ‘Act of Itself.’

When examining definitions of euthanasia, it is important to examine the ‘intention,’ the act of itself, and the factor of serious or terminal suffering and its ‘merciful’ elimination. Grisez states that, “*Intend*, sometimes refers exclusively to the willing of an end as distinct from the choice of a means, but sometimes it refers...” (to both) “... as distinct from accepting foreseen side effects.”²³³

²³² Ministry of Health, Welfare and Sport and The Ministry of Justice. “Euthanasia The Netherland’s New Rules: The Termination of Life on Request and Assisted Suicide (Review Procedures) Act” [Online].; Kidd, D. tr., Nys, H., tr. “The Belgian Act on Euthanasia of May, 28th 2002,” Ethical Perspectives [Online] (2002) 9 (2-3); Gouvernement Luxembourgeois. “Informations et Actualités due Gouvernement Luxembourgeois: Communiqué – Guide des Soins Palliatifs” [Online]; Materstvedt, L., Clark, D., Ellershaw, J., Førde, R., Gravgaard, A., Müller-Busch, H., Porta i Sales, J., Rapin, C. “Euthanasia and Physician-Assisted Suicide: A View From An EAPC Ethics Task Force.” Palliative Medicine (2003) 97-101 at 98; Singer, P. Practical Ethics, 2nd ed., (1993) 176.

²³³ Grisez, G. The Way of The Lord Jesus, Vol. 2, Living A Christian Life (1993) 470.

MacLean considers euthanasia to be intentionally ending the life of a suffering person.²³⁴ However, the Belgian definition adds that this should be when the person requests it and in the Netherlands definition, the suffering has to be unbearable.²³⁵ The intention to alleviate suffering and/or unbearable pain in a patient is legitimate, but the deliberate choice of an act or an omission in order to cause their death as the means to do this is very problematic.

Cahill and Singer consider that there is no difference between killing and allowing dying, because the 'intention' is the same.²³⁶ The EAPC distinguishes between administering medication to 'intentionally kill a person' because he has requested it and administering medication with the 'intention' to relieve suffering.²³⁷ However, medication can also be administered to intentionally kill a person without their consent and allowing someone to die is too broad because it may mean deliberately bringing about their death when they could and should have been helped to live. Therefore, attention needs to be given to the nature of the act performed because some substances in some circumstances may cause death. Someone might give diamorphine but without sufficient monitoring of the relationship between dosage and the control of pain, which may hasten the patient's death.

²³⁴ Maclean, A. Briefcase on Medical Law (2001) 93.

²³⁵ Kidd, D. tr., Nys, H., tr. "The Belgian Act on Euthanasia of May, 28th 2002," Ethical Perspectives [Online] (2002) 9 (2-3); Ministry of Health, Welfare and Sport and The Ministry of Justice. "Euthanasia The Netherlands New Rules: The Termination of Life on Request and Assisted Suicide (Review Procedures) Act" [Online] (2002).

²³⁶ Cahill, L. "Notes on Moral Theology: Bioethical Decisions to End Life." Theological Studies (1991) 52, 107-127 at 120; Singer, P. Practical Ethics, 2nd ed., (1993) 207, 209.

²³⁷ Materstvedt, L., Clark, D., Ellershaw, J., Førde, R., Gravgaard, A., Müller-Busch, H., Porta i Sales, J., Rapin, C. "Euthanasia and Physician-Assisted Suicide: A View From An EAPC Ethics Task Force." Palliative Medicine (2003) 97-101 at 98.

1.12.4 Forms of Euthanasia

Although some people with a narrow definition restrict euthanasia to voluntary euthanasia, their perspective is the intentional killing of a suffering human being. Voluntary, involuntary and non-voluntary are important in that these are different forms of euthanasia. It is certainly true to say that voluntary euthanasia is not done against the patient's wishes, but, involuntary or non-voluntary could be worse. However, this does not necessarily make voluntary euthanasia right.

1.13 Summary

As we have seen there are definitions of euthanasia which are too narrow, because they define 'voluntary' euthanasia, administered by a physician, as being the only true form of euthanasia, and there are definitions that are so broad that the patient cannot withdraw or refuse extraordinary means legitimately. The intention of the perpetrator is always important, but where the one conducting euthanasia directly intends only to eliminate suffering, if he deliberately chooses an act which of itself causes death, he commits euthanasia, hence the working definition for this thesis as,

“an action or an omission (of an action) which of itself or by intention causes death, in order that all suffering may in this way be eliminated”²³⁸

Further examination of the doctrinal teachings of the Catholic Church and their moral implications for nurses who are Christian Catholics in relation to end-of-life decision-making and euthanasia will be discussed in chapter six.

²³⁸ Jura et bona, 512.

In chapter two, the researcher will present a review of a selection of nursing research studies, which relate to the complexities that nurses confront in terms of their attitudes, beliefs, roles and experiences, when dealing with end-of-life issues and euthanasia.

CHAPTER TWO

NURSING LITERATURE REVIEW

2.1 Introduction

De Beer et al. state that much of the literature on euthanasia focuses on the involvement of physicians without consideration of nurses who play a central role in the care of terminally ill patients.¹ In this chapter, the researcher attempts to redress this balance by reviewing a selection of research studies which relate to nurses' attitudes, beliefs, roles and experiences when dealing with end-of-life issues and euthanasia.

2.2 Nurses' Attitudes to and Views on Euthanasia

There are many factors which could influence nurses' attitudes to and views on euthanasia however, nurses can be confused as to what constitutes euthanasia when determining the difference between killing and letting die, ordinary and extraordinary treatment, the use of painkillers and the doctrine of double effect and whether artificial nutrition and hydration (ANH) are regarded as medical treatment and therefore, may be withheld or withdrawn.

2.2.1 Nurses' Understanding of Euthanasia and Their Speciality

Many nurses think they understand the difference between active and passive euthanasia, but express uncertainty of their standing within the law.² This section examines four studies related to nurses from a variety of specialities and four related to

¹ De Beer, T., Gastmans, C., Dierckx de Casterlé, B. "Involvement of Nurses in Euthanasia: A Review of The Literature." *Journal of Medical Ethics* (2004) 30: 494-498 at 498.

² McInerney, F., Seibold, C. "Nurses' Definitions of and Attitudes Towards Euthanasia". *Journal of Advanced Nursing* [Online] (1995) 22 (1).

nurses from a palliative care speciality to determine if their understanding of euthanasia and/or their speciality influences their attitudes to euthanasia.

2.2.1.1 Nurses From a Variety of Specialities

In McInerney and Seibold's qualitative study, undertaken in Tasmania in 1995, euthanasia was defined as being both "active, any action that intentionally ends the life of someone else, on the request of the person, and passive, the deliberate inducement of death by withholding treatment or nourishment necessary to maintain life."³ This study was undertaken prior to the Northern Territory "Rights of the Terminally Ill Act 1995," which decriminalised voluntary active euthanasia, introduced in July, 1996, and repealed in March, 1997.⁴ Although the literature published at the time assumed that nurses' definitions of euthanasia and consequent opinions on decision-making were unproblematic, the ten nurses in this study, from a variety of specialities, displayed some uncertainty in their knowledge of what euthanasia means.⁵

For nine of the nurses, active euthanasia meant, "the deliberate taking of a life" or "the assistance of a person to death" and passive euthanasia meant "withholding treatment."⁶ However, in the definition offered for this study, active euthanasia is limited to that of being voluntary and passive euthanasia does not include the voluntariness of the patient's request or 'withdrawing treatment.' Since one nurse expressed difficulties in

³ Ibid.

⁴ Ibid.

Legislative Assembly of The Northern Territory. "The Rights of The terminally Ill (ROTI) Act, 1995" [Online].

⁵ McInerney, F., Seibold, C. "Nurses' Definitions of and Attitudes Towards Euthanasia". Journal of Advanced Nursing [Online] (1995) 22 (1).

⁶ Ibid.

making a decision whether to withdraw or continue a patient's treatment, "withdrawal of treatment" should not be excluded as a possible form of euthanasia.⁷

In general, the participants were cautious in their approach to euthanasia and did not want any legislation that would introduce euthanasia and "open the floodgates," since, in their opinion, there was the potential for abuse, especially towards the more vulnerable patient.⁸ This opinion may have been due to their uncertainty of what constitutes euthanasia, as well as the possibility that, since they came from a variety of specialities, their exposure to end-of-life decision-making may have been minimal.

Some definitions of euthanasia do not include 'passive euthanasia' since euthanasia can be considered to be 'active' by definition and so 'passive' euthanasia is considered a contradiction in terms.⁹ In Kitchener's larger postal survey, undertaken in the Australian Capital Territory (ACT) in late 1996, the majority of the 1,218 nurses (n=2000) who responded from a variety of specialities, supported voluntary active euthanasia (VAE)¹⁰ The survey occurred at a time when the "Rights of the Terminally Ill Act 1995" was legal in the Northern Territory of Australia between July, 1996, and prior to it being subsequently repealed in March, 1997.¹¹

In this study, VAE was defined as, "the practice of hastening a person's death, through such means as a lethal injection, which is carried out with the patient's knowledge and

⁷ Ibid.

⁸ Ibid.

⁹ Materstvedt, L., Clark, D., Ellershaw, J., Førde, R., Gravgaard, A., Müller-Busch, H., Porta i Sales, J., Rapin, C. "Euthanasia and Physician-Assisted Suicide: A View From An EAPC Ethics Task Force." *Palliative Medicine* (2003) 97-101 at 98.

¹⁰ Kitchener, B. "Nurse Characteristics and Attitudes to Active Voluntary Euthanasia: A Survey in The Australian Capital Territory." *Journal of Advanced Nursing* [Online] (1998) 28 (1). [Betty Kitchener, RN, School of Nursing, University of Canberra, Belconnen, ACT, Australia].

¹¹ Legislative Assembly of The Northern Territory. "The Rights of The terminally Ill (ROTI) Act, 1995" [Online].

consent....or by a patient being provided with the means to commit suicide.”¹² However, this definition does not state that the patient has ‘requested’ voluntary active euthanasia, only that he has given consent to a decision which may have been made for him and to which he then consented, thus compromising the validity of euthanasia being voluntary.

Unlike McInerney and Seibold’s Tasmanian qualitative study, nurses’ responses in this ACT survey appeared to express a confidence in their understanding of what euthanasia means; however, this would be difficult to assess fully, since nurses would not have the opportunity to clarify either of the two questions asked. The first, “Should the law be changed to allow doctors to take active steps to bring about a patient’s death, under some circumstances?” is ambiguous because it does not determine what the ‘circumstances’ may be and whether the patient has requested euthanasia. This question, therefore, could also be referring to involuntary and non-voluntary euthanasia and of the 61% nurses who responded (1218) where 69% agreed that the law should be changed, they may not have been aware of this ambiguity. This may be the reason why those in favour of euthanasia were in the majority, worked in critical care (which has an aggressive, life-saving ethos), or mental health specialities, but had little contact with people who were terminally ill and took no or only some interest in the issue of VAE, whilst those less in favour of changing the law worked in palliative care (where the ethos is one of accepting death and providing care at the end of life), or, aged care and reported a lot of interest in the issue of VAE.¹³ It is possible that those less in favour and who were more exposed to end-of-life decision-making, were aware that the question could also be referring to different forms of euthanasia.

¹² Kitchener, B. “Nurse Characteristics and Attitudes to Active Voluntary Euthanasia: A Survey in The Australian Capital Territory.” Journal of Advanced Nursing [Online] (1998) 28 (1).

¹³ Ibid.

The second question, “If euthanasia were legal, and an incurably ill patient asked the doctor to hasten his or her death, would you be willing to be involved in the provision of this request?”, does not determine whether death is imminent or whether the person is suffering, and could mean that patients with long term chronic conditions, who were considered to be incurable, could ask for and receive euthanasia.¹⁴ Similar to the response to the first question, the majority of those who were willing to be involved in the provision of a request for euthanasia worked in the area of critical care whilst those not willing to be involved were the palliative care nurses. Whilst McNerney and Seibold’s small qualitative study used a broad definition of euthanasia as being active and passive and nurses from a variety of specialities rejected the legalisation of euthanasia, in this larger survey where the definition referred to voluntary active euthanasia, only those who were in palliative care and aged care specialities rejected euthanasia and the majority agreed with the legalisation of euthanasia.

Another term used is that of ‘voluntary euthanasia’ which could be referring to both active and passive euthanasia. However, in Young and Ogden’s postal survey in Canada, targeting ninety English-speaking members of the Canadian Association for Nurses in AIDS Care (CANAC) and seventy English-speaking nurses identified as working primarily in HIV/AIDS care, ‘voluntary euthanasia’ is defined as, “the administration of a treatment or an act that induces death, at the request of the patient (e.g., a lethal injection) and ‘assisted suicide’ as where the patient is provided with the means to commit suicide.” Both ‘voluntary euthanasia’ and ‘assisted suicide’ may,

¹⁴ Ibid.

therefore, be perceived by nurses as 'voluntary active euthanasia' since both are an act that induces death at the request of the patient.¹⁵

The majority of respondents (42 or 91%) agreed that the patient did have the right to refuse treatment even if that meant death.¹⁶ However, in this definition 'administration of a treatment' implies that death is therapeutic to the patient, a term which could have confused nurses and may have consequences for the patient if s/he were compromised by pain-relieving medication and did not understand fully what 'treatment' meant. Confusion is evidenced in the responses of three respondents who were not sure if they had "assisted in the death of a patient," although twenty-one respondents stated they had "assisted in the death of a patient" and the twenty-one had not.¹⁷ "Assisted in the death of a patient" is the expression that is used, but the meaning is unclear and could mean providing words of comfort or giving pain relief, or active intervention to enable the patient's death, and therefore euthanasia.

The majority of nurses who responded (73% of 45) did not consider VE or AS as being morally as wrong, even though in Canada at that time the law stated that an act of euthanasia was murder and carried a life sentence and counselling or assisting suicide was punishable with a maximum penalty of fourteen years imprisonment.¹⁸ They perceived 'suffering' as more morally wrong than hastening death and agreed that the law should be changed to allow physicians to practise voluntary euthanasia and assisted suicide (VEAAS).¹⁹ There was, however, a general unwillingness to be involved in giving medication for the purpose of VE (91%) and AS (89%), if it were legalised and

¹⁵ Young, M.G. Ogden, R.D. "End-of-Life Issues: A Survey of English-Speaking Canadian Nurses in AIDS care. Journal of The Association of Nurses in Aids Care (1998) 9 (2) 18-25 at 20, 21, 23.

¹⁶ Maclean, A. Briefcase on Medical Law (2001) 93.

¹⁷ Young, M.G. Ogden, R.D. "End-of-Life Issues: A Survey of English-Speaking Canadian Nurses in AIDS care. Journal of The Association of Nurses in Aids Care (1998) 9 (2) 18-25 at 20, 23.

¹⁸ Ibid. at 21.

¹⁹ Ibid., at 21.

most nurses agreed that, if palliative care were provided for all terminally ill patients, this would reduce the requests for VE and AS, significantly.²⁰

When making the decision that someone should be administered euthanasia or physician assisted suicide, nurses are concerned about safeguards, which are not always considered effective.²¹ In Kowalski's American survey, undertaken in 1997, targeting two thousand randomly selected nurses in Nevada, where the majority (53%) of the 538 nurses who responded (27%) believed that physician assisted suicide (PAS), was ethically acceptable, (47% unethical), several nurses referred to the "Holland situation," stating that the elderly may feel pressurised to request euthanasia so as not to be a burden on society.²² Others referred to Hitler's selective termination of life as a possible product of legalised euthanasia, although, whilst this cannot be dismissed entirely, it is difficult to know if the participants were aware that the Nazi euthanasia programme was not legal, even in terms of the laws of the Third Reich.²³

In this study, which was undertaken prior to, the "Oregon Death with Dignity Act" passed on October 27, 1997, there may have been some confusion with terminology.²⁴ Physician assisted suicide is defined as, "where a mentally competent and terminally ill patient voluntarily requests physician assistance to end his life and is provided the necessary means and/or information to do so."²⁵ The survey questionnaire consisted of four parts and compared nurses' beliefs regarding withdrawal of life-support measures

²⁰ Ibid., at 21, 22.

²¹ Kowalski, S. "Nevada Nurses' Attitudes Regarding Physician-Assisted Suicide." Clinical Nurse Specialist [Online] (1997) 11 (13).

²² Ibid.; Ministry of Health, Welfare and Sport and The Ministry of Justice. "Euthanasia The Netherland's New Rules: The Termination of Life on Request and Assisted Suicide (Review Procedures) Act" (Ministry of Health, Welfare and Sport and The Ministry of Justice, Den Haag, 2002) n, 6.

²³ Burleigh, M. The Third Reich ((Pan Books, London, 2001) 383.

²⁴ State of Oregon. "State of Oregon Death with Dignity Act - Legislative Statute." [Online] (2004).

²⁵ Kowalski, S. "Nevada Nurses' Attitudes Regarding Physician-Assisted Suicide." Clinical Nurse Specialist [Online] (1997) 11 (13).

(92% agree, n=489), double-effect euthanasia (85% agree, n=447), PAS (53% agree, n=280) and active euthanasia (44% agree, n=235).²⁶ Unfortunately, the researchers may have inadvertently presented a misleading definition of “double-effect euthanasia,” since an act under the principle of double-effect is *not* euthanasia if the intention of administering pain-relieving medication is to promote comfort and relieve suffering, even at the risk of shortening the patient’s life.²⁷ This is evidenced in the response from some participants who considered that the patient had the right to self-determination and that it was acceptable that pain relief medication shortened life prematurely.²⁸

What is drawn from these four studies is that there is some confusion about what constitutes euthanasia amongst nurses who work in a variety of specialities where exposure to end-of-life decision-making may be minimal. As Beširević claims this is often compounded by the scientific and technological advances which expand the types of therapeutic treatments that can sustain or prolong the lives of patients.²⁹ In some societies, this is overcome by encouraging the provision of end-of-life ‘advanced directives’ so that patients can be empowered with the necessary planning tools in the event that they may not have capacity to make decisions.³⁰ The difficulty is that, where the patient is unconscious and families struggle to make surrogate decisions on behalf of the patient, often these are no more than a reflection of the family’s preference, rather than those of the patient.³¹ Many nurses view euthanasia as a last option when other palliative alternatives have been exhausted and where the patient’s ‘suffering’ has

²⁶ Ibid.

²⁷ CCC, n. 2279.

²⁸ Kowalski, S. “Nevada Nurses’ Attitudes Regarding Physician-Assisted Suicide.” Clinical Nurse Specialist [Online] (1997) 11 (13).

²⁹ Beširević, V. “End-Of-Life Care in The 21st Century: Advance Directives in Universal Rights Discourse.” Bioethics (2010) 24 (3) 105-112 at 105.

³⁰ Ibid., at 106-107.

³¹ Moorman, S., Hauser, R., “Do Older Adults Know their Spouses’ End-Of-Life Treatment Preferences?” Research on Aging (2009) 31 (4) 463-491 at 473.

become intolerable.³² The following four studies are examined in order to determine if the attitudes of palliative care nurses, who have a greater exposure to end-of-life decision-making than other nurses, differ from those in general specialities.

2.2.1.2 Nurses from a Palliative Care Speciality

Palliative care nurses who are frequently exposed to end-of-life decision-making are sometimes in favour of euthanasia and it is necessary to examine if they too understand what euthanasia means or whether, as revealed in the following four studies, there is confusion with the terminology and these factors may influence their attitudes.

Kuuppelomäki's small qualitative study was undertaken in Finland in 2000, prior to the introduction of "The Netherlands Act" (2002) in the Netherlands where voluntary active euthanasia was legalised. This study involved thirteen nurses working in cancer care and, although the study was related to 'active euthanasia,' in order to ensure that there was no ambiguity, the researchers referred to euthanasia as being both "active, meaning that the patient is given lethal medicine which speeds up his/her death and can be voluntary or involuntary and, passive, meaning that nothing active is done if a patient cannot be cured...."³³ Since participants also accepted active euthanasia for mentally incompetent patients (non-voluntary euthanasia); this could mean there may have been confusion with the forms of euthanasia.³⁴

This study, part of a larger research project, carried out in two central hospitals and four health centres and involving four groups of people (32 patients with incurable cancer, 13 relatives, 13 medical doctors, 13 nurses) was designed to study "how a patient with

³² Verpoort, C., Gastmans, C., Dierckx de Casterlé, B. "Palliative Care Nurses' Views on Euthanasia." *Journal of Advanced Nursing* (2004) 47 (6) 592-600 at 595.

³³ Kuuppelomäki, M. "Attitudes of Cancer Patients, Their Family Members and Health Professionals Toward Active Euthanasia." *European Journal of Cancer Care* (2000) 9: 16-21 at 16, 20.

³⁴ *Ibid.*, at 18.

incurable cancer suffers and attempts to deal with this suffering.”³⁵ One aspect of this study is the researcher’s apparent bias towards the practice of euthanasia being perceived as ‘positive.’ The majority of nurses (8 or 62%), who considered voluntary active euthanasia being acceptable and ethically justifiable were described as having a ‘positive attitude.’³⁶ As in Kowalski’s American survey of nurses from a variety of specialities, there was concern about adequate safeguards. Four (31%) of the five nurses were fearful that “the doors would be open for potential abuse” and disagreed that active euthanasia was justifiable and their view was that the focus should be on ridding the patient of pain, not on ending his/her life.³⁷ They were described as having “negative attitudes”; one nurse had no opinion.³⁸

However, contrary to Kuupelmaki’s findings, in Asai et al.’s larger postal survey of Japanese palliative care nurses, members of the Japanese Association of Palliative Medicine, where 68% (145 of 217 surveyed) responded, only a minority of nurses considered voluntary euthanasia (VE) ethically or legally acceptable.³⁹ In a world-view context, this survey was also undertaken prior to “The Netherlands Act” (2002), however, the definition refers to both active and passive euthanasia. This may not have been immediately recognisable to the participants, since it refers to: “precipitating the advent of death of a competent patient who is suffering uncontrollably and explicitly wishes to terminate his or her life by direct interference by the physician, for example, by the injection of a lethal drug.”⁴⁰ ‘Direct’ euthanasia usually refers to active euthanasia; however, the term “direct interference” could refer to passive euthanasia, such as direct

³⁵ Ibid., at 17, 18.

³⁶ Ibid., at 18-19.

³⁷ Ibid., at 19-20.

³⁸ Ibid., at 19-20.

³⁹ Asai, A., Ohnishi, M., Nagata, S., Tanida, N., Yamazaki, Y. “Doctors’ and Nurses’ Attitudes Towards and Experiences of Voluntary Euthanasia: Survey of Members of The Japanese Association of Palliative Medicine.” *Journal of Medical Ethics* (2001) 27: 324-330.

⁴⁰ Ibid., at 324.

interference by withdrawing ordinary or proportionate life-sustaining treatment. Since there would be no opportunity to seek further clarification in a postal survey, the results, which indicate that only a minority of nurses considered VE acceptable where the patient is terminally ill and in irreversible pain, may or may not be valid.⁴¹ However, there is evidence to suggest that Japanese culture influences nurses to reject voluntary euthanasia, as found in Tanida et al.'s comparative survey undertaken in Japan and which revealed several differences between Japanese and Australian palliative care nurses towards voluntary active euthanasia (VAE).⁴² Although most of the nurses agreed that the patient's request for VAE could be acceptable, (85% Japanese and 95% Australian), only a minority of Japanese nurses compared to Australian nurses agreed with legalising euthanasia.⁴³

The first survey of Australian nurses with a sample size of 462 (n=943, 49% response) was undertaken in 1991, five years *prior* to the "Rights of the Terminally Ill Act" in the Northern Territory of Australia.⁴⁴ The Japanese survey of 145 palliative care nurses (68% response) was undertaken in 1999, two years *prior* to "The Netherlands Act" on April 10, 2002.⁴⁵ This is significant because some of the questions refer to "The Netherlands Situation," but this was in reference to the accepted practice of VAE in the

⁴¹ Ibid., at 327.

⁴² Tanida, N., Asai, A., Ohnishi, M., Nagata, S., Fukui, T., Yanazaki, Y., Kuhse, H. "Voluntary Active Euthanasia and The Nurse: A Comparison of Japanese and Australian Nurses." Nursing Ethics (2002) 9 (3) 313-322 at 319.

⁴³ Ibid., at 319.

⁴⁴ Kuhse, H., Singer, P. "Voluntary Euthanasia and The Nurse: An Australian Survey." International Journal Nursing Studies (1993) 30.

⁴⁵ Tanida, N., Asai, A., Ohnishi, M., Nagata, S., Fukui, T., Yanazaki, Y., Kuhse, H. "Voluntary Active Euthanasia and The Nurse: A Comparison of Japanese and Australian Nurses." Nursing Ethics (2002) 9 (3) 313-322 at 314-315; Ministry of Health, Welfare and Sport and The Ministry of Justice. "Euthanasia The Netherlands's New Rules: The Termination of Life on Request and Assisted Suicide (Review Procedures) Act" [Online] (2002).

Netherlands at that time and *not* to “The Netherlands Act” of 2002.⁴⁶ The same questionnaire was used for both groups.

The researchers reported that they had used “concise sentences in certain questions,” to explain the definition and meaning of terms such as euthanasia and VAE and that “the forms of euthanasia (active or passive) were related to the act of the health-care professional and the request by the patient (voluntary, non-voluntary and involuntary).”⁴⁷ However, one question regarding voluntary active euthanasia stated:

“Has any patient in your care expressed a desire to hasten his or her death by interrupting treatment or by taking active measures?”⁴⁸

There are three questions in this one question, first referring to the patient’s expression of a ‘desire,’ which may not necessarily mean a request for euthanasia; second to the means by ‘interrupting treatment,’ meaning the withdrawal of treatment which could be passive euthanasia; third ‘by taking active measures,’ which could mean ‘active’ and direct euthanasia as in a lethal injection, or passive euthanasia by actively discontinuing (withdrawing) ordinary or proportionate life-sustaining treatment. If the respondents had answered “yes” to this question, it would be difficult to determine which part (or all) they were responding to and this may have influenced the results of the survey.

Responses were similar when asked if a patient had ever requested euthanasia (53% Japanese, 55% Australian).⁴⁹ However, of the Japanese nurses, only 21% thought that the “Netherlands situation” should be introduced (75% Australian), 14% agreed the law should be changed to allow VAE (75% Australian) and 14% responded in the

⁴⁶ Ibid., at 321.

⁴⁷ Ibid., at 314.

⁴⁸ Ibid., at 321.

⁴⁹ Ibid., at 316.

affirmative when asked if they would practise VAE if it were legal (65% Australian). Whilst the definitions/question remains ambiguous, the majority of Japanese palliative care nurses disagreed with the practice of voluntary active euthanasia, whilst the majority of Australian nurses agreed. Since the Japanese results are similar to Asai et al's survey, culture appears to be a predominant factor rather than speciality.

Veerport et al.'s later, but smaller, qualitative study undertaken in Belgium, between December, 2001, and April, 2002, used a convenience sample of twelve palliative care nurses, in order to discover their views on euthanasia.⁵⁰ Of those interviewed, five worked in a palliative care unit, four in a homecare team and three in a palliative support team.⁵¹ Euthanasia was not decriminalised in Belgium at the time of the study and the "Belgian Act on Euthanasia of May 28th, 2002" came later. Euthanasia is restricted to being, 'voluntary active' for those who were terminally ill, mentally competent and an adult (over 18 years) and is defined as, "the administration of lethal drugs with the explicit intention of shortening the patient's life at the patient's explicit request."⁵² This definition does not include the term 'suffering'; therefore, it is presumed that the patient may not necessarily be suffering and this may have some bearing on those nurses who indicated that it was difficult to formulate a clear position on euthanasia due to the individual nature of each person's dying process.⁵³

Several nurses viewed the use of palliative sedation, as hypocritical since, in their opinion, the use of such was intentional to reduce the consciousness of the patient and

⁵⁰ Verpoort, C., Gastmans, C., Dierckx de Casterlé, B. "Palliative Care Nurses' Views on Euthanasia." *Journal of Advanced Nursing* (2004) 47 (6) 592-600.

⁵¹ *Ibid.*, at 595.

⁵² *Ibid.*, at 593.

⁵³ *Ibid.*, at 595.

release him/her from suffering.⁵⁴ To them, there was no difference between palliative sedation and euthanasia.⁵⁵ However, there is evidence to suggest that palliative sedation is normally used to relieve the symptoms of “delirium, agitation and dyspnoea in the terminally ill” and not to relieve pain and, therefore, suffering, which is treated with analgesia.⁵⁶ In addition, in contrast to the nurses’ perceptions, the practice of administering palliative sedation is also perceived as a barrier against euthanasia.⁵⁷

An interesting aspect of this study is that nurses stated that working in the field of palliative care influenced their views on euthanasia. Those who were in favour of euthanasia and recognised the palliative alternatives stated that their views became subtler with constant exposure to suffering patients. Those not in favour of euthanasia and who were exposed to patients’ suffering became more accepting of euthanasia as an option.⁵⁸ In this study, nurses’ experiences within their palliative care speciality influenced their views on euthanasia.

Although each definition differs in these four palliative care studies and the culture context also differs, Finnish nurses and Australian nurses agreed with euthanasia, Japanese nurses did not, Belgian nurses were divided. Overall the eight studies revealed that those who favoured the legalisation of euthanasia worked in critical care, mental health care, and other general specialities. Those who were less in favour worked in palliative care or aged care. However, of the palliative care nurses, Australian nurses accepted euthanasia whilst Japanese nurses did not.

⁵⁴ Ibid., at 596.

⁵⁵ Ibid., at 596.

⁵⁶ Seymour, J., Janssens, R., Broeckaert, B. “Relieving Suffering at The End of Life: Practitioners’ Perspectives on Palliative Sedation from Three European Countries.” Social Science and Medicine (2007) 64: 1679-1691 at 1681.

⁵⁷ Ibid., at 1682.

⁵⁸ Verpoort, C., Gastmans, C., Dierckx de Casterlé, B. “Palliative Care Nurses’ Views on Euthanasia.” Journal of Advanced Nursing (2004) 47 (6) 592-600 at 595.

2.2.2 Nurses' Culture and Education

American nurses are more cautious in their approach to euthanasia and less in favour of legalisation of such, but this could be due to their being educated to Masters and Doctorate level and are, therefore, more aware of their legal responsibilities when making decisions.⁵⁹ In Davis and Slater's comparative study, between thirty American registered nurses and thirty-two Australian registered nurses, half working in an acute setting and half in a long term setting, nurses examined eight hypothetical vignettes on end-of-life decision-making and in only two, agreed on 'what would usually be done' and 'what they thought should be done.'⁶⁰ Euthanasia is defined as, "the act or practice of inducing a quiet and early death," a broad definition which could be interpreted to include the withdrawal of treatment.⁶¹ However, this study was undertaken in 1989, prior to the publication of the American Nurses' Association position paper on the ethics of withholding and withdrawing food and fluid, which historically were not thought of as treatment.⁶²

In response to one vignette, regarding an 83 year-old woman with advanced cancer of the lung and with metastasis to her brain, American nurses stated that normally she would have treatment, but, if she wished to be allowed to die, only medical treatment should cease and nursing care including food and fluid should continue.⁶³ They perceived their role as being an advocate for their patients, involving families and other health care professionals in end-of-life decisions through a formalised process of

⁵⁹ Davis, A., Slater, P. "U.S. and Australian Nurses' Attitudes and Beliefs about the Good Death." Journal of Nursing Scholarship (1989) 21 (1) 34-39 at 30; Kowalski, S. "Nevada Nurses' Attitudes Regarding Physician-Assisted Suicide." Clinical Nurse Specialist [Online] (1997) 11 (13).

⁶⁰ *Ibid.*, at 35-36.

⁶¹ *Ibid.*, at 39.

⁶² *Ibid.*, at 39.

⁶³ *Ibid.*, at 35.

conferences.⁶⁴ In their opinion, this inhibited doctors from “playing God” with patients’ lives and withholding treatment from their patients.⁶⁵

Over half of the Australian nurses considered that the 83 year old woman should be allowed to die and half that medical treatment should continue. All but one nurse thought that she should be given general nursing care and pain relief, but nourishment should not be given against her wishes.⁶⁶ (They did not comment on whether ANH should be given). Australian nurses, did not perceive themselves as the patient’s advocate and involved relatives in decision-making informally.⁶⁷ They were also less aware of the legal implications of their actions which could be due to their not being educated to degree level at that time and were inclined to refer decision-making to doctors.⁶⁸

Belgian nurses operate in a less hierarchical system than Japanese nurses and are more inclined to favour the legalisation of euthanasia, although Belgian palliative care nurses who are educated to masters degree level are divided in their opinion.⁶⁹ Japanese nurses are generally not in favour of euthanasia and in their culture the interdependence of the family and social unit supersedes the individuality of the patient.⁷⁰ Therefore, in Japan, consideration of individual patient euthanasia would be relative to whether or not

⁶⁴ Ibid., at 38.

⁶⁵ Ibid., at 38, 39.

⁶⁶ Ibid., at 35.

⁶⁷ Ibid., at 38.

⁶⁸ Ibid., at 39.

⁶⁹ Tanida, N., Asai, A., Ohnishi, M., Nagata, S., Fukui, T., Yanazaki, Y., Kuhse, H. “Voluntary Active Euthanasia and The Nurse: A Comparison of Japanese and Australian Nurses.” Nursing Ethics (2002) 9 (3) 313-322 at 318; Asai, A., Ohnishi, M., Nagata, S., Tanida, N., Yamazaki, Y. “Doctors’ and Nurses’ Attitudes Towards and Experiences of Voluntary Euthanasia: Survey of Members of The Japanese Association of Palliative Medicine.” Journal of Medical Ethics (2001) 27: 324-330 at 328;

⁷⁰ Asai, A., Ohnishi, M., Nagata, S., Tanida, N., Yamazaki, Y. “Doctors’ and Nurses’ Attitudes Towards and Experiences of Voluntary Euthanasia: Survey of Members of The Japanese Association of Palliative Medicine.” Journal of Medical Ethics (2001) 27: 324-330 at 329.

euthanasia would be good for the society as a whole.⁷¹ In addition, Japanese nurses rarely make independent medical decisions, rarely give intravenous medication, have less opportunity to practise euthanasia and in 2001, operated within a rigid hierarchical system requiring them to obey doctor's orders considered to be their superior.⁷²

Although education may contribute to nurses' awareness and therefore influence their attitudes to euthanasia, culture appears to be a strong factor.

2.2.3 Nurses' Religions

Some researchers claim that opinions about euthanasia are correlated with nurses' religious beliefs.⁷³ Whilst, there could be an assumption that Christians would be less in favour of euthanasia, this is not necessarily the trend. Van Wijmen et al's Dutch study found that a majority of Christian people with strong practicing faiths could envisage requesting euthanasia in certain situations; however, this could be attributed to being part of a society where euthanasia is legal.⁷⁴ In Kowalski's American study, the majority of respondents believed that patient assisted suicide should be legalised and of these 83% were Christians (52% non-catholic Christians, 31% were Catholic).⁷⁵ At that time, the "Oregon Death with Dignity Act" was in the process of being introduced as law (October 27, 1997) and this may have stimulated public awareness of euthanasia.⁷⁶ Similarly, in Kitchener's survey in Australia, those in favour of legalising voluntary

⁷¹ Ibid., at 328.

⁷² Ibid., at 328; Tanida, N., Asai, A., Ohnishi, M., Nagata, S., Fukui, T., Yanazaki, Y., Kuhse, H. "Voluntary Active Euthanasia and The Nurse: A Comparison of Japanese and Australian Nurses." *Nursing Ethics* (2002) 9 (3) 313-322 at 318.

⁷³ Veerport, C., Gastmans, C. "Palliative Care Nurses' Views on Euthanasia." *Journal of Advanced Nursing* (2004) 47 (6) 592-600 at 593.

⁷⁴ Van Wijmen, M., Rurup, M., Pasman, H., Kaspers, P., Onwuteaka-Philipsen, B. "Advance Directives in The Netherlands: An Empirical Contribution to The Exploration of A Cross-Cultural Perspective on Advance Directives." *Bioethics* (2010) 24 (3) 118-126 at 126.

⁷⁵ Kowalski, S. "Nevada Nurses' Attitudes Regarding Physician-Assisted Suicide." *Clinical Nurse Specialist* [Online] (1997) 11 (13).

⁷⁶ State of Oregon. "State of Oregon Death with Dignity Act - Legislative Statute." [Online] (2004).

active euthanasia included those of the Anglican faith as well as those who were agnostic and atheist, although those less in favour of changing the law, were of the Catholic faith.⁷⁷ Since, the “Rights of the Terminally Ill Act, 1995” was legal in the Northern Territory at that time, again, public debate may have stimulated people’s awareness of euthanasia.⁷⁸

In Asia et al’s Japanese study, where the majority of nurses were against accepting voluntary euthanasia, 105 nurses (73%) had no religion, 21 (12%) were Buddhist, 12 (8%) Christian, 2 (1%) were of other unnamed religions.⁷⁹ In Veerport and Gastman’s small Belgian study of twelve palliative care nurses, there was no clear affirmation on their stance on euthanasia only that their experiences in palliative care could change their opinion. However, of the twelve participants, eight were Roman Catholic, two had no religious affiliation and two were liberal-humanist.

Therefore, whilst religion plays some part in influencing attitudes, there does not seem to be a definitive general pattern, implying that other factors must be taken into consideration.

2.2.4 Nurses’ Ages

The age range of those nurses participating in some of the studies was between 37.5 and 49 years. For those who considered voluntary active euthanasia being acceptable in

⁷⁷ Kitchener, B. “Nurse Characteristics and Attitudes to Active Voluntary Euthanasia: A Survey in The Australian Capital Territory.” *Journal of Advanced Nursing* [Online] (1998) 28 (1).

⁷⁸ Legislative Assembly of The Northern Territory. “The Rights of The terminally Ill (ROTI) Act, 1995” [Online].

⁷⁹ Asai, A., Ohnishi, M., Nagata, S., Tanida, N., Yamazaki, Y. “Doctors’ and Nurses’ Attitudes Towards and Experiences of Voluntary Euthanasia: Survey of Members of The Japanese Association of Palliative Medicine.” *Journal of Medical Ethics* (2001) 27: 324-330 at 326.

Kuuppelomäki's small study, the average age of the nurses was 37.5 years.⁸⁰ In Kowalksi's larger survey where the majority of nurses believed that physician assisted suicide (PAS) was ethically acceptable, nurses were between 40 and 49 years.⁸¹ Nurses from a palliative care speciality in Veerport and Gastman's small study who were neither for or against euthanasia, had an average age of 40.3 years.⁸² However, in Kitchener's postal survey undertaken in Australia, those in favour of euthanasia and willing to be involved with the provision of a request, were under the age of forty years and those less in favour of changing the law were older.⁸³ The researchers found that the attitudes of both young and old reflected that of the general population at large and, if this trend were to continue, as the older nurses retired, nurses' attitudes would reflect those of the young and become more in favour of legalising euthanasia.⁸⁴ Whilst age and, therefore, general life experience may be a factor in influencing attitudes to euthanasia, this could be linked to a sociological trend.

Overall, there are many factors which could influence nurses' attitudes to and views on euthanasia and these include a nurse's speciality, culture and education, religion and age. However, having an opinion on euthanasia may not necessarily determine how nurses perceive their role, if euthanasia were to be legalised.

⁸⁰ Kuuppelomäki, M. "Attitudes of Cancer Patients, Their Family Members and Health Professionals Toward Active Euthanasia." *European Journal of Cancer Care* (2000) 9: 16-21 at 17.

⁸¹ Kowalski, S. "Nevada Nurses' Attitudes Regarding Physician-Assisted Suicide." *Clinical Nurse Specialist* [Online] (1997) 11 (13).

⁸² Verpoort, C., Gastmans, C., Dierckx de Casterlé, B. "Palliative Care Nurses' Views on Euthanasia." *Journal of Advanced Nursing* (2004) 47 (6) 592-600 at 595.

⁸³ Kitchener, B. "Nurse Characteristics and Attitudes to Active Voluntary Euthanasia: A Survey in The Australian Capital Territory." *Journal of Advanced Nursing* [Online] (1998) 28 (1). [Betty Kitchener, RN, School of Nursing, University of Canberra, Belconnen, ACT, Australia].

⁸⁴ Ibid.

2.3 The Role of The Nurse in Euthanasia

Of those nurses who are willing to practise euthanasia, the patient's suffering is often the motivating factor and there is evidence to suggest that some nurses who refrain from the practice, do so only because it is illegal.⁸⁵ In this section, of the three studies examined, in two Dutch studies, undertaken prior to "The Netherlands Act" in 2002, doctors, at that time, were allowed to terminate a patient's life under certain conditions.⁸⁶ However, Van de Scheur and Van der Arend's qualitative study, which examines the nurse's role in euthanasia, including cooperation between physicians and nurses, conclude that legalising euthanasia would not dispense with nurses' difficulties in supporting patients and their relatives.⁸⁷

The study, undertaken four years prior to "The Netherlands Act" (2002), involving twenty nurses from different wards in one hospital, defined euthanasia as, "an action that ends the life of a person on his explicit request."⁸⁸ The definition was restricted to voluntary active euthanasia and the study revealed that nurses perceived their role as supporting the patient during the request stage by assessing his genuine needs and passing on the information to the doctor.⁸⁹ However, those nurses who objected conscientiously to euthanasia found it difficult to care for the patient prior to the day that euthanasia was to be carried out and, since they did not agree with this action, could not support the patient.⁹⁰

⁸⁵ Van de Scheur, A., Van der Arend, A. "The Role of Nurses in Euthanasia: A Dutch Study". *Nursing Ethics* (1998) 5 (6) 497-508 at 502-503.

⁸⁶ Ministry of Health, Welfare and Sport and The Ministry of Justice. "Euthanasia The Netherlands's New Rules: The Termination of Life on Request and Assisted Suicide (Review Procedures) Act" [Online] (2002).

⁸⁷ Van de Scheur, A., Van der Arend, A. "The Role of Nurses in Euthanasia: A Dutch Study". *Nursing Ethics* (1998) 5 (6) 497-508.

⁸⁸ *Ibid.*, at 497.

⁸⁹ *Ibid.*, at 500-501.

⁹⁰ *Ibid.*, at 504.

Although physicians usually administered the lethal injection, sometimes nurses did so in the presence of the physician.⁹¹ Several nurses described the experience as “unreal”, knowing that “somebody had been killed.”⁹² Nurses did not discuss each other’s moral stance and this created tension, but generally, there was mutual respect for each other’s opinions and, whatever their views, most nurses regarded their role as being supportive to the patient and relatives, both before and after death.⁹³

This perception is similar to Muller et al’s qualitative/quantitative study undertaken in Amsterdam, five years prior to “The Netherlands Act” (2002), and which examines a doctor’s perspective on the co-operation between physicians and nurses with regard to euthanasia, defined as, “the intentional termination of life, by someone other than the patient, at his/her request” and, physician-assisted suicide, defined as, “intentionally helping a patient to terminate his or her life, at his or her request.”⁹⁴ What is not considered as euthanasia or assisted suicide is the discontinuation of or not starting treatment, at the request of the patient or where treatment is medically futile or providing pain-relief with the risk of shortening the patient’s life. Therefore, this definition is also restricted to voluntary active euthanasia and assisted suicide.

Despite guidelines by the Royal Dutch Medical Association, in collaboration with the nurses’ association, to determine the assignment of duties for doctors and nurses in cases of euthanasia and assisted suicide (EAAS), approximately half of the GPs, 470 (76 + 394) [Study I, 152; Study II, n= 698, 67%] and 5% clinical specialists (11 of 203

⁹¹ Ibid., at 502.

⁹² Ibid., at 503.

⁹³ Ibid. at 503.

⁹⁴ Muller, MT, Pijnenbor, L., Onwuteaka-Philipsen, B.D., Van der Wal, G. Van Eijk, J.T. “The Role of The Nurse in Active Euthanasia and Physician-Assisted Suicide.” Journal of Advanced Nursing [Online] (1997) 26 (2).

interviewed), did not consult nurses regarding a patient's request for euthanasia, or about their intention to administer euthanasia, as well as the actual administration of the drug, their reasons being, confidentiality between patient and doctor. The majority of doctors thought that nurses should never be allowed to administer EAAS and perceived their role as being restricted to supporting the patient.⁹⁵

However, it is difficult to perceive how nurses could support a patient and help prepare them for death if they are not consulted initially on the decision. Nurses are often at the front-line of receiving requests from patients, as revealed in Asch's quantitative study, undertaken in the United States of America, where of 852 nurses who worked exclusively in adult intensive care units, 141 (17%) had received requests from patients or family members to perform euthanasia or assisted suicide.⁹⁶ This study, undertaken two years prior to the introduction of the "Oregon Death with Dignity Act" on October 27, 1997, and targeting 1600 critical care nurses where 1139 responded (71%), examined the nurse's role in euthanasia and assisted suicide (EAAS) and revealed that 129 (16%) had engaged in such practices at the request of, or with tacit consent from, relatives or physicians and with the knowledge of other nurses.⁹⁷ In addition, some nurses had practised euthanasia without the knowledge of the family, but with the tacit consent of the patient. Thirty-five (4%) had hastened a patient's death by only pretending to provide prescribed life-sustaining treatment.⁹⁸ In total, 164 nurses (19%) had acted in some way to hasten a patient's death.⁹⁹

⁹⁵ Ibid.

⁹⁶ Asch, David A. "The Role of Critical Care Nurses in Euthanasia and Assisted Suicide." The New England Journal of Medicine [Online] (1996) 334 (21).

⁹⁷ Ibid.

⁹⁸ Ibid.

⁹⁹ Ibid.

The terms active euthanasia and assisted suicide were used to reflect, “circumstances in which someone performs an act with the specific intent of causing or hastening a patient’s death, including providing an intentional overdose of narcotics or potassium chloride and providing explicit advice to patients about how to commit suicide”; however, the voluntariness of the patient’s request was not expressly examined. Nevertheless, the majority of nurses embraced euthanasia as a positive act, perceiving their role as relieving the patient’s suffering.¹⁰⁰ This could place the patient at risk of involuntary and non-voluntary euthanasia, as was evidenced in a survey in Belgium in 2007, where it was found that of those nurses working in care homes who responded 27% (120) administered life-ending drugs without the patient’s explicit request.¹⁰¹

These three studies reveal that ‘suffering’ seems to be a motivating factor in nurses’ willingness to participate in euthanasia, even without the knowledge of the relatives which might put patients at risk. Doctors do not agree that nurses should administer euthanasia, but agree with nurses’ perceptions of their main role being to care for the patient before and after death. However, those nurses who object conscientiously to euthanasia experience difficulties in supporting the patient, since they do not agree with what is being done. Therefore, as Van de Scheur and Van der Arend concluded and, as these three studies reveal, legalising euthanasia would not dispense with nurses’ difficulties in supporting patients and their relatives.¹⁰² This is revealed more fully in the following two studies.

¹⁰⁰ Ibid.

¹⁰¹ Inghelbrecht, E., Bilsen, J., Mortier, F., Deliens, L. “The Role of Nurses in Physician-Assisted Deaths in Belgium” Canadian Medical Association Journal of Research [Online] (2010) May 17. [Early release, subject to revision.].

¹⁰² Van de Scheur, A., Van der Arend, A. “The Role of Nurses in Euthanasia: A Dutch Study”. Nursing Ethics (1998) 5 (6) 497-508.

2.4 Nurses' Lived Experiences of Euthanasia through the Withdrawal of Nutrition and Hydration.

Through the experience of allowing a patient in a 'persistent vegetative state' to die by withdrawing ANH, in Hollow's phenomenological study in New Zealand, five registered nurses (three female, 2 male) recognised the importance of specific mechanisms that are required to support the process.¹⁰³ Prior to the withdrawal of ANH, nurses considered it important to reflect on the moral issues concerned, recognising the "moral struggle and emotional investment" which the nurse-patient relationship demands and the necessity for a support system.¹⁰⁴

In the Tony Bland case the Law Lords accepted that clinicians might feel uncomfortable with withdrawing ANH from a non-competent patient, because of their moral stance on the sanctity of life, but considered that this stance could impede doctors' decision-making.¹⁰⁵ Nurses are concerned that patients may suffer when ANH is withdrawn, especially since current opinion has urged caution in relation to those patients with disorders of consciousness, including the vegetative state, where recent brain imaging research has indicated that patients may in fact be conscious and may suffer as a result of being deprived of ANH.¹⁰⁶

By implementing support mechanisms, nurses found that they could confront the issues and reduce their personal and professional emotional turmoil. First, there is "coping

¹⁰³ Hollows, K. "The Lived Experience of Registered Nurses Involved in The Withdrawal of Nutrition and Hydration in A Persistent Vegetative State (PVS) Patient." *Nursing Praxis in New Zealand* (1995)10 (1) 28-37 at 31-32; Legislative Assembly of The Northern Territory. "The Rights of The terminally Ill (ROTI) Act, 1995" [Online].

¹⁰⁴ *Ibid.*, 34-35.

¹⁰⁵ Crown Court: Family Division. "Judgment: Airedale NHS Trust-v-Bland Family Division [1992] 2 WLR 316 (19 November 1992)." *Lawindexpro – Case Law* [Online].

¹⁰⁶ Hohwy, J., Reutens, D. "A Case for Increased Caution in End-Of-Life Decisions for Disorders of Consciousness." *Monash Bioethic Review* [Online] (2009) 28 (2).

through ‘thinking’ where nurses would place themselves in the patient’s position of being dependent and non-cognitive, reflecting that, if they were that patient, they would not want to live in a persistent vegetative state; second, support through ‘talking’, being able to talk to colleagues informally in trying to make sense of the situation, talking to a chaplain and professional counsellor, as well as continuing dialogue with team members to bring closure to the experience of allowing a patient to die; third, decision-making being kept ‘in-house’ with the family and central care giving team.”¹⁰⁷ If those mechanisms were not available or implemented, the experience was negative.¹⁰⁸ However, Van der Riet et al’s qualitative study undertaken in New South Wales, Australia, thirteen years after Hollow’s study in New Zealand, eleven years after the repeal of the Northern Territory “Rights of the Terminally Ill Act 1995,” in March, 1997, exploring palliative care nurses’ and doctors’ perceptions and attitudes to patient nutrition and hydration at the end of life, found that, where patients were dying naturally, as long as adequate mouth care was given, they did not appear to suffer.¹⁰⁹

This study which took place in two different palliative care settings, one twenty-bed unit in a tertiary referral service for 800,000 patients with approximately 225 patients on the palliative care nursing service and one ten-bed unit within a rural hospital with approximately 74 patients in the palliative care service at any one time, involved fifteen nurses working in two separate palliative care units who were interviewed in two focus

¹⁰⁷ Hollows, K. “The Lived Experience of Registered Nurses Involved in The Withdrawal of Nutrition and Hydration in A Persistent Vegetative State (PVS) Patient.” Nursing Praxis in New Zealand (1995)10 (1) 28-37 at 28.

¹⁰⁸ Ibid., at 31.

¹⁰⁹ Van der Riet, P., Good, P., Higgins, I, Sneesby, L. “Palliative Care Professionals’ Perceptions of Nutrition and Hydration at The End Of Life.” International Journal of Palliative Nursing (2008) 14 (3) 145-151.

groups and four doctors from the tertiary palliative care unit who were interviewed individually.¹¹⁰

Whilst doctors perceive the removal of ANH as removing an added physical and psychological burden and allowing the patient to die, relatives and nurses perceive this as “promoting” the patient’s death, even in the terminal phase where s/he is less conscious and, therefore, less able to receive fluids.¹¹¹ The provision of nutrition and hydration is associated by nurses and families as being linked to “compassion and nurturing” a symbol of providing life and dehydration likened to “someone in the desert” and linked to suffering and abandoning the patient.¹¹²

Therefore, in order to cope with the situation of allowing a patient to die through the withdrawal of ANH, nurses utilise their coping mechanisms and guide the family through the difficult physical, emotional and spiritual transition towards the inevitability of the patient’s impending death. This enables them to cope with their own emotional and professional difficulties in allowing a patient to die.¹¹³

2.5 Nurses’ Roles and Experiences in the Care of the Dying

As Andolsen asserts, “nurses appreciate the way the ethics of care makes the activity of caring a practice central to human morality.”¹¹⁴ In caring for the dying patient, nurses, in their role as advocate, provide the families with information and options relative to their values and goals in order to enable them to make decisions for the patient, or with

¹¹⁰ Ibid. at 147.

¹¹¹ Ibid., at 148, 149.

¹¹² Ibid., at 148.

¹¹³ McSteen, K., Peden-McAlpine, C. “The Role of the Nurse as Advocate in Ethically Difficult Care Situations With Dying Patients.” *Journal of Hospice and Palliative Nursing* [Online] (2006) 8 (05).

¹¹⁴ Andolsen, B. “Care and Justice as Moral Values for Nurses in An Era of Managed Care” in, Cates, D., Lauritzen, P., eds. *Medicine and The Ethics of Care* (Georgetown University Press, Washington, 2001) 41-68 at 41.

the patient.¹¹⁵ In McSteen and Peden-McAlpine's qualitative phenomenological study, undertaken in the United States of America in 2008, just prior to the "Washington Death with Dignity Act", passed on November 4, 2008 being enacted on March 5, 2009, the participants, seven registered nurses with a minimum of five years nursing experience working with terminally ill patients, revealed that this often meant that they had to set aside their own values and priorities as they faced the competing ethical values of patient autonomy and beneficence.¹¹⁶

Nurses encountered many difficult ethical situations relating to decisions on 'life-support,' especially considering when it is appropriate to allow someone to die, as well as dealing with others' incompetent management of care at the end of life including inadequate pain and symptom control and a lack of attention to emotional and spiritual suffering.¹¹⁷ Decision-making can be hindered by the perceptions of all those involved (patient, family, staff) of when it is appropriate to give pain relief and opioid acceptability is often complicated by the patient's interpretation of pain, other symptoms of his illness and medication side-effects.¹¹⁸ Providing appropriate strategies to manage physical symptoms such as dyspnoea and pain becomes essential in ensuring quality care.¹¹⁹

¹¹⁵ McSteen, K., Peden-McAlpine, C. "The Role of the Nurse as Advocate in Ethically Difficult Care Situations With Dying Patients." Journal of Hospice and Palliative Nursing [Online] (2006) 8 (05).

¹¹⁶ Ibid.

¹¹⁷ Ibid.

¹¹⁸ Reid, C.M., Gooberman-Hill, R., Hanks, G.W. "Opioid Analgesics for Cancer Pain: Symptom Control for the Living or Comfort for the Dying? A Qualitative Study to Investigate the Factors influencing the Decision to Accept Morphine for Pain Caused by Cancer." Annals of Oncology (2008) 19 (1) 44-48.

¹¹⁹ Goodridge, D., Bond, J., Cameron, C., McKean, E. "End-of-Life Care in a Nursing Home: A Study of Family, Nurse and Healthcare Aide Perspectives." International Journal of Palliative Nursing (2005) 11 (5) 226-232 at 230, 231.

However, as Watson et al.'s qualitative/quantitative study undertaken in Scotland revealed, nurses often lack knowledge of palliative care drugs and in controlling end-of-life symptoms and find it difficult to distinguish between pain and agitation, assuming that dying in itself is painful.¹²⁰ This study, undertaken in the same year that The House of Lords rejected the "Assisted Dying for The Terminally Ill Bill" in England, on May 12, 2006, and prior to Margaret MacDonald's (MSP) "The Proposed End-of-Life Choices (Scotland) Bill: Consultation Document (2008)," involved eight nursing homes (72 invited, 14 responded, 8 selected) participating in the implementation of an adapted version of the 'Liverpool Care Pathway for the Dying.'¹²¹ However, what is revealed in this study is that both doctors and nurses lacked understanding of the dying process and had a tendency to strive to keep the patient alive, viewing death in itself as a failure.¹²² This resulted in doctors prescribing antibiotics for the patient, even though death was imminent and there was no hope of recovery.¹²³ Nurses were often reluctant to openly discuss dying with the residents, but compromised end-of-life care by "going along" with what the G.P. suggested, even if they considered that the treatment was inadequate.¹²⁴

When co-ordinating the care of the dying patient and in order to gain a balanced perspective of the patient's needs, nurses, in Goodridge et al's study, considered it important that they include the care staff, other professionals, as well as family

¹²⁰ Watson, J., Hockley, J., Dewar, B. "Barriers to Implementing an Integrated Care Pathway for The Last Days of Life in Nursing Homes." *International Journal of Palliative Nursing* (2006) 12 (6) 234-240 at 236.

¹²¹ Ibid., at 234. ['Liverpool Care Pathway' – A multi-professional document and evidence-based framework which provides guidance on different aspects of holistic care at the end of the patient's life.]

¹²² Ibid., at 236-237.

¹²³ Ibid., at 237.

¹²⁴ Ibid. at 238.

members.¹²⁵ This exploratory study which sought to examine the perspectives of fourteen registered nurses, eight health-care aides and family members' perspectives of the last 72 hours of nursing home residents' lives, was undertaken in Canada in 2005, four years prior to Francine Lalonde's (MP) introduction of Bill C-384 to legalise euthanasia, and in a Commonwealth context, just prior to the "Assisted Dying for The Terminally Ill Bill," being rejected by the House of Lords on May 12, 2006, in England. Nurses in the study found that relatives were concerned about the resident's death, especially fears of the resident dying alone and expressed the necessity of ensuring that relatives were cared for, educated and nurtured during the process.¹²⁶ Bloomer et al. stress the importance of family presence at a patient's death especially where life support has been withdrawn and where the patient may live for a further one to six hours.¹²⁷ Similar to Watson et al.'s findings where nurses and doctors sometimes perceived death as a failure, Bloomer found that families also perceived death as a failure.¹²⁸ This emphasises the importance of incorporating into the overall care strategy, the provision of 'nurturance' to the families, including emotional support, food and drinks as well as material comforts. Educating family members should include an explanation of the symptoms of dying and what to expect following the death.¹²⁹ This will enable families to come to terms with their loss and to reflect on the death of their loved one which they will perceive as being either good or bad at the time or later on reflection.

¹²⁵ Goodridge, D., Bond, J., Cameron, C., McKean, E. "End-of-Life Care in a Nursing Home: A Study of Family, Nurse and Healthcare Aide Perspectives." International Journal of Palliative Nursing (2005) 11 (5) 226-232 at 229.

¹²⁶ *Ibid.*, at 226.

¹²⁷ Bloomer, M., Tiruvoipati, R., Tsiripillis, M., Botha, J. "End-Of-Life Management of Adult Patients in an Australian Metropolitan Intensive Care Unit: A Retrospective Observational Study. Australian Critical Care (2010) 23: 13-19 at 17.

¹²⁸ *Ibid.*, at 14.

¹²⁹ Watson, J., Hockley, J., Dewar, B. "Barriers to Implementing an Integrated Care Pathway for The Last Days of Life in Nursing Homes." International Journal of Palliative Nursing (2006) 12 (6) 234-240 at 236-237 at 229.

As acknowledged in end-of-life care in general, in Costello's qualitative study undertaken in England, nurses perceived 'good deaths' as being where the patient experiences a 'natural' and 'peaceful' death, with no distressing symptoms.¹³⁰ This allows nurses time to plan the dying process, cope with the relative's needs and make arrangements for the death and eventual disposal of the body.¹³¹ The event of death is, therefore, less stressful for both the nurses and relatives.

This study, was undertaken prior to the proposed 'House Of Lords: Assisted Dying for The Terminally Ill Bill [HL]' in 2006, but in a European context after the decriminalisation of euthanasia in the Netherlands and Belgium in 2002 and consisted of in-depth interviews with a convenience sample of twenty-nine registered nurses to explore their experiences of death and dying based on their experience from within three care of the elderly wards in two hospitals.¹³² Nurses perceived a 'bad death' as being sudden, unexpected, where relatives are not present and occurs at a time when the impact on the ward routine is significant and/or where there is a shortage of staff.¹³³ The suddenness of death prevents the nurse from preparing the family for such an event, as well as arranging for the patient to be provided with the necessary spiritual care or religious rites. Where patients die in pain or with unrelieved suffering, nurses experience guilt and a sense of failure.¹³⁴

Although these three qualitative studies, that is McSteen and Peden-McAlpine's in the USA, Goodridge in Canada, Costello in England and one qualitative/qualitative study,

¹³⁰ Costello, J. "Dying Well: Nurses' Experiences of 'Good and Bad' Deaths in Hospital." *Journal of Advanced Nursing* (2006) 54 (5) 594-601 at 597; Seymour, J., Janssens, R., Broeckaert, B. "Relieving Suffering at The End of Life: Practitioners' Perspectives on Palliative Sedation from Three European Countries." *Social Science and Medicine* (2007) 64: 1679-1691 at 1680.

¹³¹ Ibid. at 598.

¹³² Ibid. at 596.

¹³³ Ibid. at 597.

¹³⁴ Ibid. at 598-599.

that is Watson in Scotland, are undertaken in different countries, the findings reveal that nurses perceive their role when caring for the dying patient as supporting the patient and the family through the dying process, enabling the patient to make autonomous choices whilst dying pain-free and prepared for death. However, as identified in Costello's study, nurses often lack knowledge of the dying process and palliative medication and can compromise end-of-life care by going along with the doctor's suggestion, even if they disagreed.¹³⁵ This can impact on the patient and relative's experience of what may be perceived as a good or bad death. At organisational level, nurses prefer to manage the death process in order to minimise impact on the ward routine. In doing so, nurses are prepared emotionally to cope with the dying process.¹³⁶

2.6 Conclusion

This review has illuminated the complex problems in end-of-life care and where nurses do not understand fully what constitutes euthanasia how this can impact on clinical judgments.¹³⁷ When determining nurses' attitudes to and views on euthanasia, several factors emerged which could influence nurses, such as the speciality within which they worked, their culture and education, their religion and age. Nurses from the palliative care speciality were less in favour of euthanasia, as were nurses from the Japanese culture, but there was no clear consensus of whether religion influenced nurses attitudes to euthanasia, since Christians, Buddhist, others with unnamed religions, as well as agnostic and atheist supported the legalisation of euthanasia. Catholics as a group within the Christian community were less in favour of euthanasia, as were nurses over the age

¹³⁵Watson, J., Hockley, J., Dewar, B. "Barriers to Implementing an Integrated Care Pathway for The Last Days of Life in Nursing Homes." International Journal of Palliative Nursing (2006) 12 (6) 234-240 at 238.

¹³⁶ Costello, J. "Dying Well: Nurses' Experiences of 'Good and Bad' Deaths in Hospital." Journal of Advanced Nursing (2006) 54 (5) 594-601 at 594.

¹³⁷ McInerney, F., Seibold, C. "Nurses' Definitions of and Attitudes Towards Euthanasia". Journal of Advanced Nursing [Online] (1995) 22 (1).

of forty years compared to nurses under the age of forty years who supported legalising euthanasia. This reflected contemporary society's views as a whole and could be linked to life experience and exposure to end-of-life situations.

A nurse's role in euthanasia is perceived as supporting the patient before and after death, but not necessarily administering the lethal dose, whilst those who had experienced allowing a patient to die through the withdrawal of ANH require mechanisms to cope with the withdrawal of a provision linked to compassion and nurturing. When caring for the dying patient, nurses experience difficulties in decision-making, especially where the family are involved and difficulty in ensuring the management of quality care and adequate pain-relief. However, supporting the family as well as the patient, is a key role in their overall care strategy, enabling them to provide a good or bad death experience.

These issues will be discussed further in Chapter Five and, in Chapter Six, further examination of the doctrinal teachings of the Catholic Church and their moral implications for nurses who are Christian Catholics in relation to end-of-life decision-making and euthanasia will be discussed in relation to these issues, including implications for nurses who object conscientiously to participating in euthanasia.

In Chapter Three, the qualitative research design adopted for the empirical research will be discussed, followed by a presentation of the findings in Chapter Four.

CHAPTER THREE

RESEARCH DESIGN

A Qualitative Investigation Of Nurses' Experiences On End-Of-Life Decision-Making, Through Interview-Based Study: Methodological Considerations

3.1 Introduction and Aim

The purpose of the empirical research is to explore how nurses make decisions on end-of-life care within private care homes in order to discuss how the legalisation of euthanasia could impact on the nurse's role in caring for the patient, in the light of Christian moral principles. In order to meet the aim, the researcher needed to recruit nurses, explore the phenomenon with them, analyse their experiences and discuss the findings from a moral theological viewpoint.

This chapter sets out the issues encountered in designing and conducting a qualitative interview-based study and the importance of ensuring rigour in qualitative research.

3.2 The Phenomenon of Interest

The researcher's interest in the phenomenon stemmed from her expertise of working in care homes at senior management level. Nurses working in private care homes are in a unique position when making decisions on end-of-life care, since they may be the only registered nurse on duty and, in the absence of a resident medical practitioner, may be

the key person in making decisions.¹ The researcher sought to discover what factors influenced nurses and their moral issues of concern when making end-of-life decisions.

3.3 The Research Methodology

The “research methodology,” refers to the philosophical attitude of the research, with all its characteristics from a human science perspective, which will guide the research procedure through the reduction or vocative dimensions.² Creswell states that qualitative research is concerned with “text and image data” and this has implications for the data collection strategy.³ The aim of reduction is to re-achieve direct contact with the world by bracketing or suspending of our everyday “natural attitude.”⁴ The aim of the vocative dimension is to let things “speak” or be “heard” by bringing them into nearness through the vocative power of language.”⁵ By describing the lived experience, we express a non-cognitive understanding of how we find ourselves at any given time.⁶

Without a suitable philosophical framework, the researcher would find it difficult to plan the enquiry in order to discover the essences when analysing the data.⁷ Since the research inquiry was concerned with nursing ethics and morality (“ethical inquiry”), the phenomenon related to value systems, conscience, duty, choice, intention,

¹ Department of Health. Care Homes for Older People: National Minimum Standards (Her Majesty's Stationery Office, London, 2002) 33-34, 6: 27, 28.

² Van Manen, M. “Inquiry: Methodology.” Phenomenology Online [Online] (2002).

³ Creswell, J. Research Design: Qualitative, Quantitative and Mixed Methods Approaches, 3rd. ed., (Sage Publications Inc. California, USA, 2009) 173.

⁴ Van Manen, M. “Inquiry: Reductio.” Phenomenology Online [Online].

⁵ Van Manen, M. “Inquiry: Vocatio.” Phenomenology Online [Online].

⁶ Ibid.

⁷ Polit, D., Beck, C. Nursing Research: Principles and Methods, 7th ed., (Lippincott Williams & Wilkins, 2004) 47, 253.

responsibility, right and wrong.⁸ A rigorous research design would ensure that all the issues concerned would be explored to provide quality data.

3.4 The Research Design: A Qualitative Approach

Qualitative research is described as a “systematic, interactive, subjective approach used to describe life experiences and give them meaning.”⁹ The researcher identifies a specific group (in this research, nurses who worked in care homes) and seeks to establish the meaning of the phenomenon from the views of the participants.¹⁰ This means that the study is exploratory and the researcher seeks to build an understanding of the phenomenon (in this research, nurses’ experiences on making end-of-life decisions within private care homes) based on what the participants tell her.¹¹

In order to meet the aim of the study, it was important that the researcher selected a design that would ensure that she would access the information she required and that the data generated were rich and would reflect the experiences of the participants, thus allowing insight into the phenomenon.¹² This meant that the research design would need to ensure an appropriate method for gathering information on the nurses’ experiences, which would include human actions and motives that are concerned with the ethical themes of freedom, responsibility and choice.

⁸ Burns, N., Groves, S. The Practice of Nursing Research: Conduct, Critique and Utilization, 5th ed., (Elsevier Saunders, Missouri, USA, 2005) 27.

⁹ Ibid., 23.

¹⁰ Creswell, J. Research Design: Qualitative, Quantitative and Mixed Methods Approaches, 3rd. ed., (2009) 16.

¹¹ Ibid. 26.

¹² Brink, P. “Issues of Reliability and Validity” In Morse, J., ed., Qualitative Nursing Research, 2nd. ed. (Sage Publications, Inc., California, 1991) 164-186 at 167.

As a dynamic profession, nursing involves a holistic approach to care where patient and nurse interact to express a unique behavioural experience.¹³ By interviewing nurses and allowing them to “speak out” and through the analysis of unstructured information, the researcher sought to discover the conscious or subconscious motives for nurses’ decisions and actions when making end-of-life decisions.¹⁴

However, any inquiry had to be undertaken within the researcher’s available material and financial resources, taking into consideration her full time employment commitments and adhering to the time-frame within which to complete the research.¹⁵ Also to be considered when discussing end-of-life issues was the impact on the nurse-participants and the need to ensure that they would not come to any harm.

Two interview designs were considered; the following is a discussion on why focus groups, as a method, was rejected and why the researcher used individual interviews with a small number of participants.

3.4.1 Design One: Qualitative Interviewing: Focus Groups (This Design Was Considered and Rejected)

3.4.1.1 Structure

This design entailed conducting ten semi-structured focus groups of nurses working in private care homes throughout the United Kingdom (UK), providing an opportunity purposively to sample nurses who have views on the topic. Since the topic is sensitive, a

¹³ Parahoo, K. Nursing Research: Principles, Process and Issues ((Palgrave, Basingstoke, 1997) 60, 67.

¹⁴ Ibid. 67.; Van Manen, M. “Inquiry: Vocatio.” Phenomenology Online [Online].

¹⁵ Streubert, H., Carpenter, D. Qualitative Research in Nursing: Advancing the Humanistic Imperative, 2nd ed., (Lippincott, Philadelphia, 1999) 56.

maximum of six nurses per group would be sufficient, using an interview guide as a tool, to extract the data and control the discussion.¹⁶

Some problems may arise if the researcher is the scribe and valuable information may be lost. If a scribe is used, there may be difficulty in recording all responses. If a tape recorder is used, those nearest the group may be the only ones recorded. Since the group cannot be replicated, the reliability and validity of the data may be difficult to ascertain.¹⁷ Furthermore, reliance on volunteers in a large geographical area may introduce bias into the findings.¹⁸ In order to validate the research, triangulation as a method can be used to confirm the findings.¹⁹ This could be undertaken using a quantitative survey of two hundred nurses in care homes, throughout the United Kingdom, using a questionnaire, based on the findings of the focus groups, as a tool to gather the information.

3.4.1.2 Ethical Considerations in Focus Groups

Due to the public environment of a focus group, and the sensitive topic, participants may feel inhibited in giving personal viewpoints, thus depriving the research of rich experiential data. Ethical issues arising in the use of focus groups were also considered, as follows:

¹⁶ Polit, D., Beck, C. *Nursing Research: Principles and Methods* (2004) 342.

¹⁷ Parahoo, K. *Nursing Research: Principles, Process and Issues* (1997) 299.

¹⁸ Ibid., 298.

¹⁹ Begley, C. "Using Triangulation in Nursing Research." *Journal of Advanced Nursing* [Online] (1996) 24 (1).

1. **Protecting the Participants from Harm:** The discussion may contribute to psychological harm through personal and other participants' memories or attitudes expressed in the group.
2. **Professional Debriefing Sessions:** These may be required, even if there was an opportunity for discussion during or after the interview.
3. **Skills and Resources for Professional Debriefing Sessions:** This would be in excess of the researcher's financial and material resources and professional abilities.
4. **Risk to Emotionally Disturbed Individuals:** Without an appropriate gatekeeper, those who volunteer to be part of a focus group, may be at risk emotionally. It would be unprofessional to expose any nurse to this level of unnecessary and avoidable risk.²⁰
5. **Patient Care Issues:** These may arise during the course of an interview and could not be ignored; an employer might need to be informed and the focus group would no longer be confidential.
6. **Confidentiality and Anonymity Cannot be Guaranteed in a Focus Group:** The participants may not maintain each other's confidentiality or that of others outside of the group.

²⁰ Ersser, S., "Ethnography in Clinical Situations: An Ethical Appraisal" in De Raeve, L., ed., Nursing Research: An Ethical And Legal Appraisal (Baillière Tindall, London, 1996) 49.

7. **Confession of a Crime:** A participant may confess to committing euthanasia. This would require an immediate halt to the group discussion and the possibility of a very lengthy legal process involving the entire focus group, risking the well-being of the individuals and cessation of the research project.
8. **Pilot Interview with Colleagues:** The ethical difficulties for group participants also applied to colleagues. It would also have been problematic, in terms of working relationships, if a colleague admitted to participating in euthanasia, illegally.

3.4.1.3 Conclusion

Group discussion on end-of-life issues can be ethically problematic, may possibly put the participants at risk and cause difficulties by the researcher not recognising and responding to someone who is emotionally distressed. The focus group method of inquiry was considered inappropriate for the research investigation and, therefore, was rejected.

3.4.2 Design Two: Qualitative Interviewing: Individual Interviews (This Design was Adopted for the Study).

The researcher decided to gain access to nurses working in care homes throughout the north of Scotland, in an area that was, to her, geographically accessible. Her intention was to enable nurses through the interview process to recollect past experiences, intentions and actions and bring those experiences to the researcher in the present time.

The point of the interview was to collect information and, therefore, it was important to consider all the issues in designing an interview-based study.²¹ There are many advantages in using interviews to collect data and interviewing one person at a time assures care of the participant and control of the conversation, which would not have been possible if focus groups were used.

3.4.2.1 Advantages:

- 1. Flexible:** Interviewing is a flexible technique allowing the researcher to use her interpersonal skills to explore a greater depth of meaning.²²
- 2. Generation of Rich Data:** The rapport between participant and researcher enables the generation of rich experiential data, since the researcher is able to gain immediate responses to her questions and this allows further probing, or building on previous responses.²³ It is a powerful way of gaining access to people's "perceptions, meanings, definitions of situations and constructions of reality."²⁴
- 3. Type of Interview:** There are various types of interview structure to support the interview process such as, "the "informal conversational interview; the interview guide approach, the standardized open-ended interviews."²⁵ The structured interview

²¹ Burnard, P. "Interviewing," Nurse Researcher (RCN Publishing Company Ltd., Middlesex, 2005) 13 (1) 4-6 at 5.

²² Burns, N., Grove, S. The Practice of Nursing Research, 5th ed., (2005) 397.

²³ Pontin, D. "Interview" in Cormack, D., ed., The Research Process in Nursing, 4th ed. (Blackwell Sciences Ltd., London, 2000) 289-299 at 297.

²⁴ Punch, K. Introduction to Social Research: Quantitative and Qualitative Approaches, 2nd. ed. (Sage Publications Ltd., London, 2005) 168; Fontana, A., Frey, J. "The Interview" In Denzin, N., Lincoln, Y., eds. Handbook of Qualitative Research, 2nd ed. (Sage Publications Ltd., Thousand Oaks, 2000) 645-672 at 645.

²⁵ Cohen, L., Manion, L., Morrison, K. Research Methods in Education, 5th ed., (Routledge Falmer, London, 2000) 270-271; Punch, K. Introduction to Social Research: Quantitative and Qualitative Approaches, 2nd. ed. (2005) 169.

is often regarded as one of the easiest to process as it enables the researcher to ask the same questions and process the data by gathering all the responses from each question.²⁶ The semi-structured interview offers the participant an opportunity to express his experience freely and using an aide-memoire ensures that the main issues are covered, but it can be more time-consuming and difficult when processing the data.²⁷ The unstructured interview enables the interview to be matched to the individual and the circumstance and allows data to emerge without any influence from the interviewer, but data organisation and analysis can be difficult.²⁸ The semi-structured interview method was chosen for this study.

4. **Length of an Interview:** An interview can be a one-time event or it can take place over many sessions.²⁹ Therefore, the researcher is able to determine what is the most appropriate for the outcome of the research, the participant and the researcher's parameters.

However, there are many aspects to the interview process that need to be carefully considered in the research design:

3.4.2.2 Ethical Considerations

1. **Ethical Approval:** It was necessary that the researcher seek ethical approval for the study, so she considered carefully how she would a) gain access to the participants through clear official channels and b) collect the data to minimise any negative

²⁶ Burnard, P. "Interviewing," Nurse Researcher (2005) 13 (1) 4-6 at 4.

²⁷ Streubert, H., Carpenter, D. Qualitative Research in Nursing: Advancing the Humanistic Imperative (1999) 23; Burnard, P. "Interviewing," Nurse Researcher (2005) 13 (1) 4-6 at 5;

²⁸ Cohen, L., Manion, L., Morrison, K. Research Methods in Education, 5th ed., (2000) 271.

²⁹ Fontana, A., Frey, J. "The Interview" in Denzin, N., Lincoln, Y., eds. Handbook of Qualitative Research, 2nd ed. (2000) 645-672 at 646.

impact on the participant.³⁰ This process meant the development of a protocol to ensure that all aspects of the study had been considered and the presentation of this to the ethics committee.

2. Informed Consent: To ensure informed consent meant that the participants would need to be clearly informed of all the potential risks and benefits of participating in the research study.³¹

3. Impact on The Participant and Potential Risks: It is not always easy to appreciate fully the impact (both short term and long term) that the interview may have on the participant, especially where the topic may be of a sensitive or distressing nature.³² Any follow-up discussion by the researcher immediately after the interview could be biased, since the participant may not wish to discuss in full any negative impact with the person who had just interviewed her.³³ Provision for debriefing would need to be arranged if the interview was to be once only.³⁴ The researcher's past experience and professional skill in interviewing would determine how she would conduct the interview to ensure that no harm was done to the participants and their self-esteem was not undermined.³⁵

³⁰ Cohen, L., Manion, L., Morrison, K. Research Methods in Education, 5th ed., (Routledge Falmer, London, 2000) 57.

³¹ Parahoo K. Nursing Research: Principles, Process and Issues (1997) 205-206.

³² Johnson, B., Plant, H. "Collecting Data from People with Cancer and their Families: What are The Implications?" in De Raeve, L. Nursing Research: An Ethical and Legal Appraisal (Ballière Tindall, London, 1996) 85-100 at 92.

³³ Ibid. at 92.

³⁴ May, K. "Interview Techniques in Qualitative Research: Concerns and Challenges" In, Morse, J., ed., Qualitative Nursing Research: A Contemporary Dialogue, Rev. ed., (Sage Publications, Inc. California, 1991) 188-201 at 199.

³⁵ Ibid.; Cohen, L., Manion, L., Morrison, K. Research Methods in Education, 5th ed., (Routledge Falmer, London, 2000) 57.

- 4. Confidentiality and Anonymity:** The participant's right to privacy and means of protecting identification had to be considered and participants were informed of and understood the limits to the researcher's control of the research results once they were made public.³⁶ During the interview, discernment on what was casual conversation or research data needed to be considered, especially if the participant passed on something in confidence to the researcher.³⁷
- 5. Confession of a Crime:** Clear guidelines were essential in determining the limit of the discussion and the need to inform the appropriate people (employer and/or police) if the participant confessed to a crime committed in the course of her duties.
- 6. Impact on The Researcher:** Practical aspects were a major consideration. The fieldwork would be undertaken some distance from the researcher's base and, since she personally funded the research study, cost was important as was time away from her own work commitments.³⁸ Furthermore, the potential emotional impact on the researcher in discussing end-of-life issues had to be considered and she needed to put in place measures for debriefing, if required.

3.4.2.3 Gaining Access to the Participants

Gaining access had to be considered because this would eventually impact on the level of participation provided by the participants and if a gatekeeper were required it would

³⁶ Cohen, L., Manion, L., Morrison, K. Research Methods in Education, 5th ed., (2000) 60-63.

³⁷ Ibid., 66; Clarke, A. "Qualitative Interviewing: Encountering Ethical Issues and Challenges," Nurse Researcher (2006) 13 (4) 19-29 at 21.

³⁸ Johnson, B., Plant, H. "Collecting Data from People with Cancer and Their Families: What are The Implications?" in De Raeve, L. Nursing Research: An Ethical and Legal Appraisal (1996) 85-100 at 95.

be important that a rapport were established at an early stage with all those concerned with the participant³⁹

3.4.2.4 Time Structure

The researcher planned to undertake two interviews with each participant: to gather the data and, to return with the transcription to verify content and discuss any new data put forward. It was also important that the design plan made allowances for any further follow-up, if required.⁴⁰

3.5 Qualitative Interview-Based Study : Empirical Procedure

3.5.1 Gaining Ethical Clearance to Proceed with The Research Study.

Since the research involved nurses working in private care homes, it did not fall within the NHS Central Office for Research Ethics Committees (COREC), categories requiring ethical clearance.⁴¹ To gain ethical clearance for the research proposal, the researcher submitted an application, accompanied by a “Protocol,” to “The Open University Human Participants and Materials Ethics Committee.” The Protocol considered and discussed the issues related to the research study and ethical issues of concern.⁴²

³⁹ Streubert, H., Carpenter, D. Qualitative Research in Nursing: Advancing the Humanistic Imperative (1999) 24

⁴⁰ May, K. “Interview Techniques in Qualitative Research: Concerns and Challenges” in, Morse, J., ed., Qualitative Nursing Research: A Contemporary Dialogue, Rev. ed., (1991) 188-201 at 190.

⁴¹ NHS Central Office for Research Ethics Committees (COREC). [Online]

⁴² 3.5.1.1.

3.5.1.1 The Protocol Submitted to The Open University Human Participants and Materials Ethics Committee.⁴³

The Protocol included:

- Definition of Nursing and End-of-Life Care
- Definition of Euthanasia
- Duration of the Research
- Introduction and Justification for the Research
- Contribution to Knowledge
- Aims and Objectives
- Research Project and Study Design:
 - The Method
 - Overview of the Research Process.
- Recruit The Participants:
 - Recruitment of Non-English Speaking Nurses
 - Pilot Study
 - Main Study
- Sample Size
- Gathering the Data:
 - Setting,
 - Data Collection and Processing
- Managing the Data:
 - Data Analysis
 - Validation and Trustworthiness of the Data
 - Integrity of the Researcher in Analysing the Data
 - Sponsorship
 - Data Protection
- Literature Review
- Discussion
- Findings
- Ethical Implications and Risks
 - Integrity of the Researcher
 - The Introductory Letter
 - The Interview
 - Consequences of the Research
 - Data Management and Storage
 - Injustice
 - Principle of Non-Maleficence
 - Collection of Data and Processing Process
 - The Sampling Process
 - Respect for Autonomy
 - After the Interview
 - Welfare of the Researcher
- Bibliography

⁴³ The Protocol is not included in the appendices since the information is discussed in this chapter.

Approval to conduct the study was received on 1 June, 2004, provided that two recommended changes were made.⁴⁴ Final approval was given on 29 June, 2004.⁴⁵

3.5.1.2 Ethical Implications and Risks

The ethical principles underpinning the study ensured that the participants were protected from harm at all times. However, in the research study, the nurse-participants become vulnerable, for they are giving of themselves and revealing their intimate experience, thoughts and perceptions and require respect and protection.⁴⁶

3.5.1.3 Integrity of the Researcher

The researcher has forty years of nursing experience, is a registered mental health and general nurse, as well as a clinical nurse teacher and nurse tutor and, possesses a Bachelor of Science (Hons.) in Nursing and a Master of Education in Religious Education. As an accountable practitioner, therefore, she possesses the “relevant knowledge and skills” with which to undertake the research investigation and conduct interviews of a sensitive nature.⁴⁷

3.5.1.4 Unnecessary Imposition on Participants and their Patients.

Since she had undertaken an extensive literature search, the researcher was satisfied that the knowledge was not already available and that the study would not encroach on

⁴⁴ Appendix I (a) The Open University Human Participants and Materials Ethics Committee.”

⁴⁵ Appendix I (b) The Open University Human Participants and Materials Ethics Committee.”

⁴⁶ Royal College of Nursing (RCN). Research Ethics (Royal College of Nursing of The United Kingdom, London, 1998) 6.

⁴⁷ Ibid., 12 (1).

valuable time, otherwise used for the participants and their families or for their patients in the care homes.⁴⁸

3.5.1.5 Consent

The participants' rights include freedom from coercion in any form.⁴⁹ Since the Home Manager had approached each participant with the research information, the participant may have felt obliged to take part in the research study.

All research should be undertaken with participants who freely consent to participate, but who are also free to withdraw their consent at any time during the research process.⁵⁰ It is important, for the protection of the participant, that consent is informed, but because this involves a past agreement to consent, a "process consent" offers the participant the opportunity to change arrangements if necessary and negotiate with the researcher further ideas and suggestions as the research progresses.⁵¹ This requires that participants are informed of the potential risks as well as the benefits of participating in the research study and that they agree voluntarily to participate at any point during the research.⁵² Providing adequate information to the participant, preferably in writing, enables him/her to understand the risks of participating in the research, and to make a fully informed choice.⁵³ (The researcher ensured that the participants were aware of

⁴⁸ Ibid., 15.

⁴⁹ Polit, D., Beck, C. Nursing Research: Principles and Methods (2004) 147.

⁵⁰ Munhall, P. "Institutional Review of Qualitative Research Proposals: A Task of No Small Consequence" in Morse, J., ed., Qualitative Nursing Research, 2nd ed., (Sage Publications Inc., Newbury Park, 1991) 258-271 at 267.

⁵¹ Ibid. 267.

⁵² Streubert, H., Carpenter, D. Qualitative Research in Nursing: Advancing the Humanistic Imperative (1999) 167; Christians, C. "Ethics and Politics in Qualitative Research" in Denzin, N., Lincoln, Y., eds. Handbook of Qualitative Research, 2nd ed. (Sage Publications Ltd., Thousand Oaks, 2000) 133-155 at 139t

⁵³ Benton, D., Cormack, D., "Gaining Access to The Research Site" In Cormack, D., ed., The Research Process in Nursing, 4th ed. (Blackwell Sciences Ltd., London, 2000) 129-137 at 135.

potential risks).⁵⁴ This is especially important where questions can be of a sensitive nature and where there is a potential for psychological harm.⁵⁵

It is necessary, therefore, to give the participant time to reflect on the nature of the research study, to read the information unhurriedly and to question any aspect that is unclear.⁵⁶ The researcher addressed these concerns related to consent by ensuring that the participant was given information explaining the research in detail, without any deception which could influence the decision to participate.⁵⁷

First, the Home Manager was asked to identify a possible candidate and ask if she would consider participating in the research study, including undertaking an interview.⁵⁸

If the nurse expressed an interest, she was given a package which contained a letter of invitation,⁵⁹ an Information Sheet,⁶⁰ an Interview Guide,⁶¹ a consent form agreeing to participate,⁶² a consent form agreeing for use of an audiotape,⁶³ the form guaranteeing non-duplication of audiotapes.⁶⁴ She was then invited to read the information over the next seven days and, after seven days, to decide whether s/he wished to participate in the research study. If s/he wished to ask any questions that might influence the decision

⁵⁴ Appendix III (a) - "Invitation to take Part in a Research Pilot Interview," 1-7 at 5.

⁵⁵ McHaffie, H. "Ethical Issues in Research" in Cormack, D., ed., The Research Process in Nursing, 4th ed. (Blackwell Sciences Ltd., London, 2000) 51-61 at 55.

⁵⁶ *Ibid.*, 55.

⁵⁷ Christians, C. "Ethics and Politics in Qualitative Research" in Denzin, N., Lincoln, Y., eds. Handbook of Qualitative Research, 2nd ed. (2000) 133-155 at 140.

⁵⁸ Appendix II - Letter of Invitation to Gatekeeper.

⁵⁹ Appendix III (a) - Invitation to take Part in a Research Pilot Interview; Appendix III (b) - Invitation to take Part in a Research Study of Nurses [top page only: same content as III (a)].

⁶⁰ Appendix IV- Information Sheet.

⁶¹ Appendix.V - Interview Guide

⁶² Appendix.VI - Consent – Agreement to Participate.

⁶³ Appendix.VII- Consent – Agreement for use of an Audiotape during the Research Interview Process.

⁶⁴ Appendix VIII – Guarantee that the Audiotape will not be Duplicated.

to participate, s/he was encouraged to do so.⁶⁵ The participant was assured that participation in the research study was completely voluntary and at no stage should s/he feel any pressure to respond to the invitation to be part of the research study.⁶⁶

Since the researcher was only informed of those participants who, after the seven day period, were interested in participating and had agreed to do so, there was no coercion by the researcher and the nurse was free to decline at this stage. In addition, since the nurse may have felt it necessary to comply with the Home Manager's request to participate, the researcher requested in writing that the Home Manager assure the nurse that the research study was not related to his/her current employment situation.⁶⁷ Furthermore, the nurse was given the opportunity to withdraw from the research at any point of the study.

3.5.1.6 Confidentiality and Anonymity

The participants were assured of complete confidentiality and anonymity and that neither their name nor address would be used at any point in the research process. They were also verbally assured that the data could be retrieved from the researcher and destroyed at any time in the research study, prior to completion of the study.

3.5.1.7 Protecting the Participants from Harm

Only emotionally mature participants were selected for the research study and the participant's introductory letter included a suggestion, in the event of any emotional

⁶⁵ Appendix II – Letter of Invitation to Gatekeeper, 1-3 at 2.

⁶⁶ Appendix III (a) - "Invitation to take Part in a Research Pilot Interview," 1-7 at 2.

⁶⁷ Appendix.II - Letter of Invitation to Gatekeeper, 1-3 at 3.

distress, to contact their doctor or the Samaritans' twenty-four hour national contact number provided.⁶⁸

Prior to the interview, the researcher and participant agreed on a time limit for the interview, in order to prevent participant and researcher exhaustion. Participant fatigue can alter data accuracy and therefore the validity of the research. Furthermore any verbal or non-verbal signs of fatigue and anxiety were monitored.⁶⁹ The participant was made aware that the interview could be concluded, at their request, at any time.

3.5.1.8 Use of the Information

In the covering letter the participants were informed of the nature of the research and that the data were part of a research study to be analysed and discussed in a doctoral thesis undertaken by the researcher.⁷⁰ They were also informed that it may not be possible for the researcher to control the dissemination of the research results once it was out in the public arena.⁷¹

This research, conducted under the auspices of the Maryvale Institute and of the Open University will be used in education, research and publication.⁷² The researcher

⁶⁸ Royal College of Nursing (RCN) Research Ethics (Royal College Of Nursing Of The United Kingdom, London, 1998) 25.

⁶⁹ Deatrix J., Faux, S. "Conducting Qualitative Studies with Children and Adolescents" in Morse, J. , ed.,. Qualitative Nursing Research, 2nd ed., (Sage Publications Inc., Newbury Park, 1991) 216.

⁷⁰ Rogers, J, Ethical Issues in Survey Research" In De Raeve, L., ed ., Nursing Research: An Ethical And Legal Appraisal (1996) 24.

⁷¹ Appendices VI, VII.

⁷² Appendix VII.

guaranteed that the audiotapes would be returned to each participant and destroyed in his/her presence, once the research had been completed and published.⁷³

3.5.1.9 After the Interview

The researcher kept in contact with the participants, by sending a one page letter yearly, giving a general update of the research investigation. This also assured the participants that they could contact the researcher at any time.

3.5.1.10 Welfare of the Researcher

The researcher recognised that research of a sensitive and emotional nature can be intense and this may have an effect on her personally. For this reason she arranged to have access to a registered counsellor, if required, throughout the research process.

3.5.2 Recruiting the Participants

3.5.2.1. Recruiting Participants for Pilot Interview

1. Two care homes were selected at random from a telephone book, within a city area.
2. The manager of each care home was contacted by telephone and the researcher explained who she was, the nature of the research study and enquired whether the manager would be interested to receive an information pack explaining the study.

⁷³ Ibid.

3. If the manager replied in the affirmative, the researcher sent out an “Information pack” to that nursing home, containing the following, each separate item was printed on a different colour of paper.

- A letter of introduction and explanation of the manager’s role as “gatekeeper.”⁷⁴
- A protocol with detailed explanation of the study.⁷⁵
- A invitation to the prospective participant to take part in a pilot interview (white).⁷⁶
- An Information Sheet (mauve).⁷⁷
- The Interview Guide (yellow).⁷⁸
- The Consent Form (salmon pink).⁷⁹
- The Consent Form- for use of an audiotape (blue).⁸⁰
- Guarantee of Non-Duplication of Audiotapes Form (green).⁸¹
- An Ethical Clearance Form (white) for the Manager.⁸²
- A copy of The Ethical Clearance Letters from The Open University Ethics Committee.⁸³

⁷⁴ Appendix II - Letter of Invitation to Gatekeeper.

⁷⁵ Protocol not included in the Appendix since the information is already discussed in this chapter (3.5.1.1.).

⁷⁶ Appendix III (a) - Invitation to take Part in a Research Pilot Interview, III (b) - Invitation to take Part in a Research Study of Nurses

⁷⁷ Appendix IV - Information Sheet.

⁷⁸ Appendix V - Interview Guide.

⁷⁹ Appendix VI - Consent – Agreement To Participate.

⁸⁰ Appendix VII- Consent – Agreement for use of an Audiotape during the Research Interview Process.

⁸¹ Appendix VIII – Guarantee that the Audiotape will not be Duplicated.

⁸² Appendix IX – Ethical Clearance.

⁸³ Appendix I (a) – Memorandum: Email from Joan Oates, Chair, The Open University Human Participants and Materials Ethical Committee (HPMEC) to Sylvia Hoskins, 1 June, 2004 ; Appendix I (b) Email from Joan Oates, Chair, HPMEC to Sylvia Hoskins, 29 June, 2004.

4. If the potential participant required further clarification, the manager would contact the researcher.
5. The manager contacted the researcher when a participant was confirmed. If no volunteer was found, a follow-up letter of thanks was sent to the manager
6. The “Ethical Clearance Form” was signed by the manager and returned to the researcher prior to the interview.
7. A date and time were arranged for the interview, to take place in the care home, where the manager would be available.

Of the two managers who were approached to participate in the pilot interview, only one manager contacted the researcher. Through the gatekeeper (the manager) the nurse was given an Information Sheet, explaining the nature of the research and with an invitation to participate in the research pilot interview.

A telephone call was made to the second manager and she confirmed that she had received the information, but on reflection did not have time for the research study. The researcher thanked the manager and reassured her that she understood the demands of a busy care home. The researcher did consider recruiting a second person from another care home, since this would have given her broader feedback on the interview process.

However, the pilot interview is designed to test the protocol and other aspects of the study, as well as test the researcher in her interviewing technique, in preparation for the main study. The pilot interview is extremely important because there is always a danger

of introducing bias into the interview process, which would thus impact on the validity and trustworthiness of the data. Milne and Oberle remind us that qualitative research seeks to generate insights, not to reveal “truth” and that is why the relationship between participant and researcher is regarded as an important tool to enrich the findings.⁸⁴ It is, important, therefore, that researchers ensure that the description of the reality of the experience is generated from the participants’ viewpoint and not her own.⁸⁵

A pilot interview creates an opportunity to ensure that the researcher’s method is appropriate and to ask the participants if there are any improvements that could be made in the interview process. This also enables the researcher to review the interview technique and ensure that all ethical issues are addressed within the research process.⁸⁶ At the end of the first pilot interview, after receiving meticulous and detailed feedback from the participant, the researcher was assured that the pilot interview had been a satisfactory experience to both participant and researcher.

3.5.2.2 Recruiting Participants for Main Study

Once the pilot interview had been completed, eighteen care homes in the north of Scotland were selected from the telephone book, with a purposeful selection of gaining diversity by targeting specific geographical areas. All care homes provided a service for the elderly and some included specialists units for those with dementia or those who were terminally ill. Eleven managers confirmed positively, but only ten managers were able to recruit volunteer nurses. Seven managers did not reply and further contact was

⁸⁴ Milne, J., Oberle, K. “Enhancing Rigor in Qualitative Description,” Journal of Wound Ostomy and Continence Nursing (2005) 32 (6) 413-420 at 413.

⁸⁵ Ibid.

⁸⁶ Polit, D., Beck, C. Nursing Research: Principles and Methods (2004) 196.

made by telephone, confirming their decision not to participate. Of those ten care home managers who replied positively, two care homes included a specialist unit for residents with dementia and one included a GP unit for the terminally ill. The criteria for selecting the participants for the pilot interview and that for the main study were exactly the same. Each nurse was invited to participate in the research study.⁸⁷

3.5.2.3 Recruitment of Nurses whose First Language is not English

There was a guarantee of competency in communicating in English, based on the criteria for registration, as determined by the Nursing and Midwifery Council.⁸⁸

3.5.2.4 Sampling

The sampling strategy should be appropriate to the research methodology and one which considers the sample size, the representativeness of the sample and the access to the sample.⁸⁹ Sandelowski states that “the obligation of researchers is to defend their sampling strategies as reasonable for their purposes.”⁹⁰ Using bias as a positive tool to facilitate the research process, the researcher sought the assistance of a “gatekeeper” the manager of each care home, to identify participants who met the criteria for the research study.⁹¹ As Morse states, an unbiased sample, chosen randomly, would violate the principle of gaining qualitative information from those who have expertise of the

⁸⁷ Appendix III (b) “Invitation to take Part in a Research Study of Nurses.” (Page 1) Pages two to seven, have not been included since they are exactly the same as pages two to seven of, Appendix III (a) “Invitation to take Part in a Research Pilot Interview.”

⁸⁸ Nursing and Midwifery Council. Registration as a Nurse or Midwife in the United Kingdom: Information for Applicants outside the European Economic Area [Online]

⁸⁹ Cohen, L., Manion, L., Morrison, K. Research Methods in Education, 5th ed., (2000) 92.

⁹⁰ Sandelowski, M. “Focus on Research Methods: Whatever Happened to Qualitative Description?” Research In Nursing & Health (2000) 23, 334-340 at 338.

⁹¹ Morse, J. “Strategies for Sampling” in Morse, J. ed. Qualitative Nursing Research, 2nd ed., (Sage Publications, London, 1991) 127-146 at 136; Benton, D., Cormack, D. “Gaining Access to the Research Site” in Cormack, D., ed. The Research Process in Nursing 4th ed. (2000) 131-137 at 131.

phenomenon.⁹² The reason for using gatekeepers was that the researcher had worked at senior management level in several care homes in the North-East of Scotland, as well as lecturing in nursing at the local university. There was, therefore, a significant chance that she would be familiar to many nurses and if they volunteered for the study, they may have offered information according to what they knew the researcher would expect (the Hawthorne Effect).⁹³ This could have diminished the credibility of the qualitative study.

However, by using gatekeepers (secondary selection) to select the participants, the researcher jeopardised the principle in qualitative research of ensuring the selection of participants who were “good informants” and who possessed the qualities of being articulate in sharing their experiences with the researcher.⁹⁴ Although the participants selected for the research had knowledge and experience of the phenomenon, only those who were available and willing to participate in the study were selected.⁹⁵

This sampling strategy, known as “convenience sampling”, or accidental or opportunity sampling, meant that only those available had a *chance* of being selected, thus excluding others who may have been more suitable for the research study.⁹⁶ In adopting this strategy, the researcher had no guarantee that the gatekeepers had selected participants who would be suitable for the research study and who would produce quality data. If the participants did not produce quality data, this would impact on the outcome of the research. [The research participants in this study were competent and

⁹² Morse, J. “Strategies for Sampling” in Morse, J. ed. Qualitative Nursing Research, 2nd ed., (Sage Publications, London, 1991) 127-146 at 138-139.

⁹³ Burns, N., Grove, S. The Practice Of Nursing Research, 5th ed., (2005) 35.

⁹⁴ Ibid., 127.

⁹⁵ Parahoo, K. Nursing Research: Principles, Process and Issues (1997) 210; Cohen, L., Manion, L., Morrison, K. Research Methods in Education, 5th ed., (2000) 143.

⁹⁶ Parahoo, K. Nursing Research: Principles, Process and Issues (1997) 230-231.

articulate and did produce quality data]. The advantage of convenience sampling, however, is that the sample is relatively easy to acquire and does not involve a great deal of financial cost to the researcher.⁹⁷

Had she wished to purposely select a representative group, it would have been essential for the researcher to have direct contact with the nurses, not use a gatekeeper, and make the necessary judgments to select those who met a specific (predetermined) criterion and who could provide the necessary data.⁹⁸ However, there are disadvantages to using purposive sampling in that the researcher may miss out on acquiring a broad range of data that comes from convenience sampling, which would contribute positively to the research findings and enhance the outcome of the study.⁹⁹

3.5.2.5 Sample Size in Qualitative Research

Generally, in qualitative research there is no specific rule or criteria for sample size and this is dependent on informational needs, the quality of the informants and the sampling strategy.¹⁰⁰ Neither a large nor a small sample size guarantees that it is representative of the population, but in qualitative research it is more likely to be small.¹⁰¹ Generalisability is not the aim, since the aim is to “describe and explain the phenomenon.”¹⁰² In addition there are many practical factors that affect sample size

⁹⁷ Macnee, C., McCabe, S. Understanding Nursing Research: Reading and Using Research in Evidence-Based Practice, 2nd. ed., (Walters Kluwer/Lippincott Williams & Wilkins, Philadelphia, 2008) 121.

⁹⁸ Cohen, L., Manion, L., Morrison, K. Research Methods in Education, 5th ed., (2000) 103; Morse, J. “Strategies for Sampling” in Morse, J. ed. Qualitative Nursing Research, 2nd ed., (1991) 127-146 at 135-136; Parahoo, K. Nursing Research: Principles, Process and Issues (1997) 232-233.

⁹⁹ Macnee, C., McCabe, S. Understanding Nursing Research: Reading and Using Research in Evidence-Based Practice, 2nd. ed., (2008) 122.

¹⁰⁰ Ibid., 68-77; Polit, D., Beck, C. Nursing Research: Principles and Methods (2004) 308.

¹⁰¹ Cohen, L., Manion, L., Morrison, K. Research Methods in Education, 5th ed., (2000) 93.

¹⁰² Brink, P. “Issues of Reliability And Validity,” In Morse, J., ed., Qualitative Nursing Research, 2nd. ed. (1991) 164-186 at 170.

including cost of travelling to the interviews as well as time available and resources, including administration resources.¹⁰³

Although saturation was not the aim, since, saturation is appropriate to a “grounded theory” method of investigation and consideration should be made to time involved with repeated interviews, the research did in fact reach a saturation point at participant eight, (out of eleven) where no further new information was contributed to the research.¹⁰⁴ In addition, due to time restraints allocated to interview the participants the sample size needed to be relatively small. The researcher, therefore, sought diversity and focused on an area in the north of Scotland where the participants worked in care homes situated in remote farming areas, fishing villages and towns communities, within a geographical area of 3,200 square miles.¹⁰⁵

Even with geographical diversity, the question remained as to whether the group of nurses recruited for the study was a representative sample of the population.¹⁰⁶ To ensure that a sample is representative, other factors should be considered such as age group and experience.¹⁰⁷ Had the sample been purposively selected, these issues would have been addressed, but in convenience sampling there is no guarantee that the population would be representative, other than they were all nurses working within a

¹⁰³ Cohen, L., Manion, L., Morrison, K. Research Methods in Education, 5th ed., (2000) 93.

¹⁰⁴ Charmaz, K. “Grounded Theory: Objectivist and Constructivist Methods” in Denzin, N., Lincoln, Y., eds. Handbook of Qualitative Research, 2nd ed. (Sage Publications Ltd., Thousand Oaks, 2000) 509-535 at 520; Morse, J. “Strategies for Sampling” in Morse, J. ed. Qualitative Nursing Research, 2nd ed., (1991) 127-146 at 141.

¹⁰⁵ Polit, D., Beck, C. Nursing Research: Principles and Methods (2004) 309.

¹⁰⁶ Cohen, L., Manion, L., Morrison, K. Research Methods in Education, 5th ed., (2000) 98.

¹⁰⁷ *Ibid.* 98.

care of the elderly setting. If the same study were to be carried out with a different group of nurses, the results may be different.¹⁰⁸

In total, out of twenty care home managers who were approached to participate in recruiting nurses for the study (including the pilot interview), eleven care home managers responded and eleven participants were recruited, one from each care home, one male and ten female. In order to preserve anonymity, all participants will be referred to as female in the presentation of the findings.

3.5.3 Data Collection

3.5.3.1 The Setting

The research interview was conducted within the care home, at a pre-arranged time with the manager and the participant thus ensuring minimal impact on the organisation. The researcher had made prior agreement that confidentiality and anonymity would be guaranteed. If the researcher recognised the participant in any way or vice-versa, the research interview would be abandoned.

3.5.3.2 Procedure for Each Interview

The conduct of each interview was as follows. The gatekeeper was present at this stage.

1. The manager (gatekeeper) introduced the participant to the researcher.
2. The researcher introduced herself as both a qualified nurse and university lecturer. She also stated her interest in moral theology.

¹⁰⁸ Ibid. 98.

3. The research study was explained to the participant, who was invited to ask any questions for clarification.
4. The Information Sheet (purple) was discussed.
5. The participant signed the “Agreement to Participate” consent form (salmon-pink). The gatekeeper signed as witness.
6. The participant signed the “Consent – Agreement for use of an Audiotape during the Research Interview Process” Form (blue). The gatekeeper signed as a witness.
7. The researcher signed the “Guarantee that the Audiotape will not be Duplicated” Form (green). The gatekeeper signed as a witness. The form was given to the participant to retain.
8. The “Information Sheet” (mauve) was discussed.
9. The “Interview Guide” (yellow) was given to the participant previously to read prior to the interview.¹⁰⁹

If there was agreement for using an audiotape, the researcher informed the participant that the tape could be stopped at any time. The gatekeeper then left the room and the interview between researcher and participant commenced.

3.5.3.3 The Interview Process (Conduct, Issues, Strengths, Weaknesses)

The collection of data through interviewing is a process that requires researcher skill, mutual respect, non-coercion, time and privacy.¹¹⁰ It is important that care is taken to ensure that the interview process is well thought through in order to ensure internal

¹⁰⁹ Parahoo, K. Nursing Research: Principles, Process and Issues (1997) 155.

¹¹⁰ Dearnley, C. “A Reflection on the Use of Semi-Structured Interviews,” Nurse Researcher (2005) 13 (1) 19-28 at 20, 26.

validity, meaning that the findings should “accurately describe the phenomena being researched.”¹¹¹ Planning the interview should include attention to the planned setting or location, as well as the duration, the timing and the conduct of the interview. This would include the researcher’s pre-determined style of “probing, listening, prompting, supporting, clarifying” and being flexible with the discussion, thus enabling participants to raise issues that may not be in the Interview Guide (or Information Sheet).¹¹² Many issues can impact on an interview, positively or negatively, including age, gender, race, class and dress.¹¹³ It is also important that the interview is planned to avoid interruptions and minimise distractions, as well as to consider the questions that may be asked so that they are not superficial.¹¹⁴

The data were collected using the following processes:

- The Researcher, as a tool for gathering information.
- Audiotape recording of interview (if consent were given).
- Writing and recording of data (if consent to use audiotape were refused).
- Interview guide - In-depth interactive interview with each participant, using an ‘Interview Guide.’
- Observational data - body language, facial expressions.

¹¹¹ Cohen, L., Manion, L., Morrison, K. Research Methods in Education, 5th ed., (2000). 107.

¹¹² Ibid. 146-147.

¹¹³ Ibid. 280.

¹¹⁴ Ibid. 280, 281.

3.5.3.3.1 The Researcher as A Tool for Gathering Information

The skill and competence of the researcher and her interviewing technique has a direct impact on the quality of the research.¹¹⁵ The researcher had many years of experience in interviewing and facilitating discussions over a forty year period, which included:

- interviewing patients in both the mental health and general health setting.
- interviewing relatives in the clinical field.
- interviewing students in her role as nurse teacher.
- facilitating small and large group discussions with undergraduate and post-graduate students.
- interviewing candidates for job positions.

In qualitative research, the researcher is responsible for the dynamic interchange in the research interviews between researcher and participant.¹¹⁶ In order to generate rich data, it is her job to ensure that she does not overwhelm the participant, thus shifting the balance of power to the researcher. It is also the researcher's role to ensure that the elements are "interpersonal and interactional," ensuring the questions are clear and non-academic, that the participants are relaxed and motivated and that the conversation flows by using techniques such as nodding her head and making sounds that show interest.¹¹⁷

¹¹⁵ Tuckett, A. "Part II. Rigour in Qualitative Research: Complexities and Solutions," Nurse Researcher (2005) 13 (1) 32.

¹¹⁶ Cohen, L., Manion, L., Morrison, K. Research Methods in Education, 5th ed., (2000) 279; Burns, N., Groves, S. The Practice of Nursing Research: Conduct, Critique and Utilization, 5th ed., (2005) 540.

¹¹⁷ Ibid. 280.

However, in spite of her experience as in interviewer, at times the researcher felt tempted to “keep the participants on track” and drive the data.¹¹⁸ This can change the pattern of the discussion and can mould the discussion according to the researcher’s perception of how it should flow. Milne and Oberle found in their own research study that developing the ability to contend with periods of silence in the conversation prevented the conversational flow from being disrupted.¹¹⁹ It therefore became important for the researcher to enable participants to become true co-constructors of meaning in the discussion and allow a dynamic and changing dialogue which reflected the reality of participants’ experiences.

3.5.3.3.1.1 Interpretive Role of the Researcher

In order to ensure validity in interviews, it is necessary to minimize the amount of bias within the interview process, which can evolve from both researcher and participant and include preconceived ideas, misperceptions and misunderstandings.¹²⁰ The characteristics of both researcher and participant can be interjected into the exchange of dialogue both positively and negatively, but the relationship between the two can also enrich the findings.¹²¹ However, there is always a risk that the researcher may misinterpret what the participant is saying or may subconsciously seek answers which support any of her pre-conceived ideas. Another problem is that the participant may misunderstand what is being asked.¹²² Throughout the interchange between interviewer and participant, the researcher was aware that her attitudes and opinions can impact on

¹¹⁸ Milne, J., Oberle, K. “Enhancing Rigor in Qualitative Description,” Journal of Wound Ostomy and Continence Nursing (2005) 32 (6) 413-420 at 417.

¹¹⁹ Ibid., 418.

¹²⁰ Cohen, L., Manion, L., Morrison, K. Research Methods in Education, 5th ed., (2000) 121.

¹²¹ Ibid., 121; Milne, J., Oberle, K. “Enhancing Rigor in Qualitative Description,” Journal of Wound Ostomy and Continence Nursing (2005) 32 (6) 413-420 at 413.

¹²² Cohen, L., Manion, L., Morrison, K. Research Methods in Education, 5th ed., (2000) 121.

the interview process. Since the researcher is also a nurse, her sense of the “pathic” in other nurses’ experiences assisted in phenomenological understanding.¹²³ However, the researcher was aware that her social, cultural and religious views may subconsciously influence how she interacted with the participant and so consciously kept this possible danger in mind during the interview process.¹²⁴

3.5.3.3.1.2 Researcher’s Dress Code

A researcher’s personal characteristics can introduce bias into the research, through the participant’s social perception of the researcher and corresponding response to the professional or casual approach to the interview.¹²⁵ Prior to one interview, the researcher realised that one participant appeared to be extremely apprehensive. On gentle probing, the participant agreed that she was slightly overawed by someone who lectured at a university (the researcher). The researcher had anticipated the possibility of this happening at some point in the research interviews and for this reason, she dressed in casual but smart attire so that her appearance assured the participant of a professional approach to the study, but encouraged the participant to feel relaxed. This mode of presenting herself at the interview remained the same throughout all the research interviews. Although the researcher expected each participant’s experience to be unique, she assumed a commonality in the shared experiences of the nurses.¹²⁶

¹²³ Ibid. 121.

¹²⁴ Ibid. 121.

¹²⁵ Parahoo, K. Nursing Research: Principles, Process and Issues (1997) 285.

¹²⁶ Hopkinson, J. “The Hidden Benefit: The Supportive Function of the Nursing Handover for Qualified Nurses Caring for Dying People in Hospital.” Journal of Clinical Nursing [Online] (2002) 11.

3.5.3.3.2 The Audio-Tape as a Research Tool

The validity of responses in interviews is enhanced by the presence of the researcher who can clarify questions and seek clarification from the participants throughout the interview process.¹²⁷ However, to ensure that she captured the responses in their totality, she endeavoured to use where possible an audio-tape. Participants one, two, five, six, seven, eight, ten and eleven agreed to the use of an audio-tape during the interviews. Tape-recording the interviews provided an accurate recording of the conversation between researcher and participant and assisted in eliminating bias during the transcribing process. However, audio-tapes are selective in that they do not record the visual and non-verbal aspects of the interview, which may change the dynamics of the data.¹²⁸ The researcher sought to eliminate this discrepancy and ensure validity by taking field notes, thus recording the participant's non-verbal responses, as well as her own thoughts at that time, for use when analysing the data at a later date.¹²⁹ This strategy also ensured that in the event of audio-tape failure, she had hand-written notes of the interview.¹³⁰

However, the researcher was concerned that the presence of the audio-tape would have a direct negative influence on the participant, contributing to feelings of anxiousness or self-consciousness.¹³¹ For this reason, the audio-tape was placed, where the quality of the recording would not be impaired, but where the visibility of the recorder was unobtrusive. Within five minutes of each interview commencing, during which time the

¹²⁷ Parahoo, K. Nursing Research: Principles, Process and Issues (1997) 296.

¹²⁸ Cohen, L., Manion, L., Morrison, K. Research Methods in Education, 5th ed., (2000) 281

¹²⁹ Ibid., 281; Tuckett, A. "Part II. Rigour in Qualitative Research: Complexities and Solutions," Nurse Researcher (2005) 13 (1) 32.

¹³⁰ Creswell, J. Research Design: Qualitative, Quantitative and Mixed Methods Approaches, 3rd. ed., (2009) 183.

¹³¹ Tuckett, A. "Part II. Rigour in Qualitative Research: Complexities and Solutions," Nurse Researcher (2005) 13 (1) 33.

researcher asked general questions about their age and experience, the participants appeared relaxed and did not indicate that the audio-tape was intrusive in any way.

3.5.3.3.3 Writing and Recording Data - Validity in Dialogue

Participants, three, four and nine, did not agree to the use of an audio-tape and the researcher transcribed the interviews herself whilst undertaking the interviews. She chose not to have a second person transcribing to ensure confidentiality although she recognised that there would have been benefits to this process had she done so and she would have been able to concentrate more fully on the interview itself.

Throughout the interviews, the researcher listened to the dialogue, focusing on the tone, intensity and expressions of the language that would assist in producing well-written anecdotal evidence in written text, thus reflecting the participants' everyday lived experience.¹³² Where a text is rich with essences, it can be presented as it is, allowing it to speak for itself, retaining the vividness and phenomenological uniqueness, hidden in the text.¹³³ When the text delivers a "feeling understanding" through the intensity of the emotional language, it brings a sense of meaningfulness to the reader, which cannot be reduced to a conceptual or intellectual phase.¹³⁴

However, transcribing the conversation whilst interviewing the participants had limitations. The researcher found it difficult to concentrate fully on the conversation when note-taking and there is always the risk that note-taking might be "off-putting" to

¹³² Van Manen, M. "Inquiry: The Revocative Turn: Lived-Throughness" [Online] (2002).

¹³³ Ibid.

¹³⁴ Van Manen, M. "Inquiry: The Convocative Turn: Appeal." [Online] (2002).

the participants.¹³⁵ The method also disrupted the flow of conversation and inhibited the interactive process between participant and researcher at times, which could have had a direct impact on the quality of the data.¹³⁶ In addition, this meant that a type of shorthand was used which relied on the researcher's memory and had the potential of being misinterpreted during the transcribing process.¹³⁷ It was necessary, therefore, prior to data analysis, to ensure that transcriptions were accurate and reflected the totality of the interview experience in order that the research was credible.¹³⁸ This difficulty was overcome by returning the transcripts to the participants for verification of their authenticity.

3.5.3.3.4 The Interview Guide and Information Sheet

Although qualitative interviewing is concerned with allowing the participants to express their experience freely, it was important to ensure that all pertinent issues related to the phenomenon were discussed in the interviews, thus providing rich, quality data. As well as providing a systematic approach to the entire research design, including the data analysis, an Interview Guide (or schedule) can support the interview by eliminating the possibility of missing an important issue.¹³⁹

The use of Interview Guides with a priori themes and categories can impact on the findings by forcing the participants to "fit their feelings and experiences into the researcher's categories," which may result in a complete distortion of the participant's

¹³⁵ Cohen, L., Manion, L., Morrison, K. Research Methods in Education, 5th ed., (2000) 281.

¹³⁶ Field, P. "Doing Fieldwork in your own Culture" In, Morse, J. ed.,. Qualitative Nursing Research, 2nd ed., (Sage Publications Inc., Newbury Park, 1991) 91-104 at 101.

¹³⁷ Cohen, L., Manion, L., Morrison, K. Research Methods in Education, 5th ed., (2000) 281.

¹³⁸ Polit, D., Beck, C. Nursing Research: Principles and Methods (2004) 572.

¹³⁹ Barbour, R. "Checklists for Improving Rigour in Qualitative Research: A Case of the Tail Wagging The Dog?" British Medical Journal [Online] (2001), 322; Kirk, S. "The Value of Qualitative Research," [Online] (2009); Parahoo, K. Nursing Research: Principles, Process and Issues (1997) 293-296.

experience and what it means to him or her.¹⁴⁰ However, Cohen et al. suggest that this can be overcome by ensuring that the Interview Guide is “sufficiently open-ended to enable the contents to be re-ordered, digression and expansions made, new avenues included and further probing to be undertaken.”¹⁴¹

Therefore, an “Information Sheet” and an “Interview Guide” were constructed, to drive the interview process. Prior to recruitment, a written invitation to participate in the study was sent to the participant, which included an “Information Sheet” identifying “Some of the Issues related to End-of-life Care”.¹⁴² This was provided at this time, to ensure the ethical principle of doing no harm and that the participant was fully aware of some of the issues that could be discussed during the interview process, that she was comfortable with discussing these issues and that it would not cause her any psychological harm.¹⁴³

The “Interview Guide,” was devised to be less specific than the “Information Sheet,” inviting the participant to “talk about anything you want,” but offering some general “triggers” with a suggestion that, if desired, the participant may refer back to the Information Sheet to remind herself of some of the issues related to end-of-life-care.¹⁴⁴

The researcher found that the Interview Guide and Information Sheet ensured that the data were participant-driven, allowing each participant to express her own individual

¹⁴⁰ Cohen, L., Manion, L., Morrison, K. Research Methods in Education (2000) 271.

¹⁴¹ Ibid., 146.

¹⁴² Appendix IV - Information Sheet.

¹⁴³ Cohen, L., Manion, L., Morrison, K. Research Methods in Education, 5th ed., (2000) 279.

¹⁴⁴ Appendix V- Interview Guide.

feelings and relate her own personal experience in a flexible discussion.¹⁴⁵ In addition, “The Information Sheet” acted as an “aide-memoire” for the researcher, enabling her to focus on the topic at hand and prompting the participant through open-ended questions, in the limited time that she had to undertake the interviews. As well as considering participant fatigue and time away from their full time employment caring for patients, the geographical diversity impacted on the time allocated to interview the participants. Travel to each participant varied from one hour to three hours by car, making a return journey from two hours to six hours, in the winter, when the weather was extremely unpredictable and the daylight time ended in the afternoon.

This did not mean that the researcher knew all the questions that she would ask during the interview; qualitative research should have minimum control in order to allow “topics and perspectives to emerge.”¹⁴⁶ That is why the “Interview Guide” was designed to be open and general, so that the questions remained broad and unconstrained.¹⁴⁷ There was no set, structured list of questions since the researcher was interested in the issues raised by the participants themselves.¹⁴⁸

However, as the interviews progressed, the researcher tended to ask some of the same questions of all the research participants, commencing with the question or statement, “Where did you train?” or “When did you train?” or “Let’s start with the year of when you were trained, followed by telling me of some of your experiences since that time.” As each participant offered their own unique experience, any new issue emerging,

¹⁴⁵ Milne, J., Oberle, K. “Enhancing Rigor in Qualitative Description,” Journal of Wound Ostomy and Continence Nursing (2005) 32 (6) 413-420 at 417.

¹⁴⁶ Parahoo, K. Nursing Research: Principles, Process and Issues (1997) 295.

¹⁴⁷ Ibid. 295, 296.

¹⁴⁸ Ibid. 294.

relating to that experience would be included when interviewing the next participant. Validity was enhanced by the presence of the researcher who was able to ensure that the participants understood the questions and, where necessary, the researcher was able to probe the participant for further responses.¹⁴⁹ Transcribing the data immediately after each interview (within twenty-four hours) reminded the researcher (by listening to the audio-tapes and reading the field notes) of all the questions that were asked.

3.5.3.3.5 Observational Data - Body Language, Facial Expressions

Interviewing is a dynamic interaction between the researcher and the participant and during the interview process body language and facial expressions can indicate to the researcher and to the participant a “true” emotion that might not be supported by the researcher’s or participant’s words. Often an action such as moving position in a chair, a frown, a hand movement can indicate that the person is confused or angry, bored or anxious and it is extremely important that the researcher is aware of these dynamics.¹⁵⁰

3.5.3.3.6 Post-Interview and Second Interview

Once the interviews had been transcribed, the researcher arranged a second interview with each participant, in order to facilitate participant validation and ensure that the interview data were accurate.¹⁵¹ This process was necessary to ensure that the researcher had not misinterpreted or misconstrued the information given to her in any way. She also wanted to re-affirm to the participant that the data were very much in their control, even though this was an interactive process involving two professional people.¹⁵²

¹⁴⁹ Ibid. 293.

¹⁵⁰ Cohen, L., Manion, L., Morrison, K. Research Methods in Education (2000) 279.

¹⁵¹ Ibid. 108.

¹⁵² Ibid. 121.

She returned the transcript from the first interview to each participant who was invited to read it, clarify any part of the data and verify that the content was accurate.¹⁵³ In addition, each was invited to contribute any further material that they had remembered since the first interview.¹⁵⁴ The second interviews were not tape-recorded, but the researcher recorded any additional material by writing notes. Each participant was satisfied that it was a valid transcript of the interview and one that recorded and reflected their experiences accurately.

The second interviews lasted from thirty minutes to forty-five minutes, depending on the time available to the participants. Since each participant was on-duty at the time, it was important that the researcher utilised the time available effectively, so as not to deprive the patients of time that would otherwise be allocated to them. However, since during the transcription process themes and categories were emerging from the data, the researcher was satisfied that she had enough data to meet the aims of the study.¹⁵⁵

The researcher discussed with the participants whether they would wish to meet again after the second interview, but all participants stated that this was not necessary since they considered that they had contributed as much information as possible to the research study. However, an agreement was made that, if they wished to contribute further information, they should contact the researcher and arrangements would be made to meet again.

¹⁵³ Brink, P. "Issues of Reliability and Validity" (1991) 180-181.

¹⁵⁴ Cohen, L., Manion, L., Morrison, K. Research Methods in Education (2000) 108.

¹⁵⁵ Rogers, J. "Ethical Issues in Survey Research" In De Raeve, L., ed., Nursing Research: An Ethical and Legal Appraisal (1996) 18-31 at 27.

The eleven interviews were conducted between October, 2004, and January, 2005. Participants had from 10 to 38 years of nursing experience (mean 19.19 years, SD (standard deviation) 8.92 years, based on this sample) and between 3 and 22 years experience of working in care homes (mean 11.95 years, SD 7.00 years based on this sample).

3.5.3.4 The Interviews: Pilot Interview – Participant One

Interview: Place, Length and Tools for Recording: The interview took place in a care home in a city. The length of the interview was one hour and forty-five minutes. An audiotape was used throughout the interview. The researcher also recorded other information by note-taking.

Prior to the interview a twenty minute discussion took place between researcher, participant and gatekeeper where all aspects of the research study were discussed in full with the participant and any questions clarified. In addition, the gatekeeper witnessed the participant signing the “Consent-Agreement to Participate Form,” and “Agreement for use of an Audiotape during the Research Interview Process” form and duly signed the forms. The Researcher signed the “Guarantee that the Audiotape will not be Duplicated” form and the gatekeeper witnessed and signed the form. This was given to the participant. (The Ethical Clearance form had previously been signed by the gatekeeper and returned to the researcher giving consent to interview one registered nurse.).

Researcher and Participant Reaction: Since this was the researcher’s first interview with one of the participants, she was anxious that everything would go well. The

participant appeared slightly anxious at first, but the time taken with the gatekeeper and the researcher to re-explain the research and to sign the forms (approximately twenty minutes) assisted her to relax. The participant enthusiastically contributed to the discussion and the atmosphere within the room was relaxed and yet vibrant as both researcher and participant co-constructed the participant's experience. Thirty-five minutes into the interview, the researcher asked the participant if she was feeling comfortable with the interview and whether she wished to continue or stop. The participant affirmed that she was happy for the interview to continue.

Post-Interview Reflection and Second Interview: Once the interview had been completed, the researcher asked the participant if there were any issues that she would like to discuss regarding the interview procedure. The participant replied that there were none. The researcher also asked if there could be any improvements to the interview technique. The participant replied that there were none. This process took fifteen minutes. The researcher asked the participant how she felt after the interview and if she would like to discuss anything brought up in the interview; the participant replied that she felt fine and there was nothing else she wished to discuss.

The researcher arranged to meet the participant for a second interview so that she could read the typed transcript and ensure that the transcript was accurate and that she was happy with it, prior to the researcher analysing the data. The interview was then concluded with an informal chat which included the Home Manager (gatekeeper), the participant and the researcher.

The Second Interview: This took place one week later, in order to validate the written transcript and ensure that it was an accurate representation of what the participant said.

Some minor changes were made to the transcript in order to clarify one or two points. The second interview lasted thirty-five minutes. No new information was added to the transcript.

3.5.3.5 The Interviews: Main Study: Participants Two to Eleven

As undertaken in the pilot interview, prior to each interview a twenty minute discussion took place between researcher, participant and gatekeeper where all aspects of the research study were discussed in full with the participant and any questions clarified. In addition, the gatekeeper witnessed the participant signing the “Consent-Agreement to Participate Form,” and “Agreement for use of an Audiotape during the Research Interview Process” form and duly signed the forms. The Researcher signed the “Guarantee that the Audiotape will not be Duplicated” form and the gatekeeper witnessed and signed the form. This was given to the participant. (The Ethical Clearance form had previously been signed by the gatekeeper and returned to the researcher giving consent to interview one registered nurse). The procedure for participant ten deviated from this routine (see below). In addition, after the interview, fifteen minutes was devoted to ensuring that the interview had not caused the participant any harm in any way and that she was satisfied with all aspects of the interview.

The length of the interviews referred to in the following individual participant interviews is exclusive of pre-interview and post-interview time.

3.5.3.5.1 Participant Two

Interview: Place, Length and Tools for Recording: The interview took place in a care home, in a small country town. The length of the interview was forty-eight minutes, and an audiotape was used throughout. The researcher also recorded other information by note-taking.

Researcher and Participant Reaction: The participant took time (ten minutes) to adjust to the audio-tape's presence, portraying an anxiousness that prompted the researcher to ask if she would prefer the audio-tape to be switched off. This was declined. Since this was the researcher's second interview and that the pilot interview had provided positive feedback, she felt more relaxed than she did with the first interview.

Second Interview: The second interview took place two weeks later and lasted twenty-five minutes. No new information was added.

3.5.3.5.2 Participant Three

Interview: Place, Length and Tools for Recording: The interview took place in a care home in a city. The length of the interview was one hour and ten minutes. An audiotape was not used. The researcher recorded the interview by note-taking.

Researcher and Participant Reaction: The participant was extremely relaxed throughout the interview process and the interchange between researcher and participant remained vibrant throughout where ideas and experiences were interchanged and discussed.

Second Interview: The second interview took place thirteen days later and lasted twenty-five minutes. No new information was added.

3.5.3.5.3 Participant Four

Interview: Place, Length and Tools for Recording: The interview took place in a care home in a small country village. The interview lasted one hour. An audiotape was *not* used and the researcher recorded the interview by note-taking.

Researcher and Participant Reaction: A relaxed interview where the participant enthusiastically offered her opinions, perceptions and experiences. Since it was late in the evening, the researcher realised that tiredness, after a very busy day, impacted on how quickly she was able to note-take.

Second Interview: The second interview took place three weeks later. The interview lasted thirty-five minutes and no new information was added.

3.5.3.5.4 Participant Five

Interview: Place, Length and Tools for Recording: The interview took place in a care home in small village in a rural farming community. The length of the interview was fifty-five minutes. An audiotape was used throughout the interview. In addition, the researcher recorded the interview by note-taking.

Researcher and Participant Reaction: The researcher was conscious of noise in the care home due to the location of the interview room. The participant was relaxed and

informative, but some noises did distract both researcher and participant and this interrupted the flow of the conversation at times.

Second Interview: The interview took place five days later and lasted forty-five minutes. The participant made several amendments to the original transcript which further clarified her experiences. She also included some additional new material and this was further explored in this interview. Although the researcher suggested the possibility of meeting for a third time to ensure that the participant was completely satisfied with the transcript, this was declined as not being necessary. However, an agreement was made that in the event she changed her mind, the researcher would be available for a further meeting.

3.5.3.5.5 Participant Six

Interview: Place, Length and Tools for Recording: The interview took place in a care home in a small village in rural farming community. The interview lasted one hour. An audiotape was used throughout the interview. In addition, the researcher recorded the interview by note-taking.

Researcher and Participant Reaction: The interview went very well, but a low flying jet overhead made it difficult for the researcher to hear the participant during one part of the conversation. The researcher did not stop the conversation and allowed the participant (who did not seem disturbed by the noise from the jet) to continue. During the transcribing process, the researcher realised that part of the audio-tape was not decipherable due to the noise from the low flying jet and, since she had not heard the conversation at that point, she did not have any notes of the participant's responses.

Important information on suffering and depression was lost. On reflection, the researcher should have paused the interview until the jet had passed.

Second Interview: The interview took place eight days later and lasted thirty minutes. The participant added some valuable information concerning her belief system, but did not add anything further on suffering.

3.5.3.5.6 Participant Seven

Interview: Place, Length and Tools for Recording: The interview took place in a care home in a large town and lasted one hour. An audiotape was used throughout the interview. In addition, the researcher recorded the interview by note-taking.

Researcher and Participant Reaction: Vibrant, interactive discussion, where the participant appeared to be extremely relaxed.

Second Interview: The interview took place nine days later and lasted thirty minutes. No new information added.

3.5.3.5.7 Participant Eight

Interview: Place, Length and Tools for Recording: The interview took place in a care home in a village in a rural farming community. It lasted one hour and seventeen minutes. An audio-tape was used throughout the interview. In addition, the researcher recorded the interview by note-taking.

Researcher and Participant Reaction: Good interactive discussion and exchange of ideas and experiences. Participant was extremely enthusiastic and wished to discuss her experiences in-depth.

Second Interview: The interview took place six days later and lasted twenty-five minutes. No new information added.

3.5.3.5.8 Participant Nine

Interview: Place, Length and Tools for Recording: The setting for this interview was a care home in a coastal village. The interview lasted one hour and ten minutes and an audio-tape was *not* used. The researcher recorded the interview by note-taking.

Researcher and Participant Reaction: The interview flowed very well, although some pauses were necessary to ensure accurate note-taking. There was a great deal of laughter when reminiscing and describing her experiences and she appeared to enjoy the interactive process with the researcher.

Second Interview: Nine days later the second interview was held and lasted thirty minutes. No new information added.

3.5.3.5.9 Participant Ten

Interview: Place, Length and Tools for Recording: The interview took place in a care home near a coastal village and lasted one hour and seven minutes. An audio-tape was used throughout the interview. In addition the researcher recorded the interview by note-taking.

Researcher and Participant Reaction: This interview was undertaken on night-duty and the participant was the only trained nurse on duty. Although a care assistant answered most of the patient call bells, the participant was required by the care assistant on two occasions to leave the interview room and tend to matters within the home. In spite of this limitation, the interview went very well. The documentation for consent had been witnessed and signed by the nursing home manager prior to the interview taking place. However, the “Agreement for use of an Audiotape during the Research Interview Process” form was only signed by the participant without a witness and the “Guarantee that the Audiotape will not be Duplicated” was signed by the researcher without a witness. (The care-assistant was not used as a witness to ensure confidentiality).

Second Interview: This interview took place ten days later, also on night-duty and lasted twenty-five minutes. No new information was added.

3.5.3.5.10 Participant Eleven

Interview: Place, Length and Tools for Recording: The interview took place in a care home in a small rural village and lasted fifty-five minutes. An audio-tape was used throughout the interview. In addition, the researcher recorded the interview by note-taking.

Researcher and Participant Reaction: The participant approached the interview with great intensity wishing to discuss many life and professional experiences. A very good interactive and vibrant discussion.

Second Interview: Nine days later the second interview took place and lasted twenty-five minutes. No new information was added.

3.5.3.6 Summary

The researcher felt very positive about the interviews and was aware that they had given both researcher and participant an opportunity to discuss important and sensitive experiences relating to end-of-life decisions. Throughout the interviews, the researcher was aware that she was gaining tremendous insight into the complexities of the topic, a position, which she had personally been distanced, since she was always in a senior management position when working for a health-care organisation that managed care homes and not on the “front-line.” Since the nurses’ experiences were presented in a fresh, new, contemporary manner, this enabled her to reflect and analyse the data from a position of objectivity, but with real insider knowledge.¹⁵⁶

3.5.4 Managing The Data

3.5.4.1 Data Storage

In order to protect the data, ensure that they were not tampered with in any way and remained pure, the data were stored in a locked unit, within a secure building. The data were inputted and stored on a secure computer to which only the researcher had access. The data were protected, stored, analysed and reported in accordance with the Data Protection Act, 1984.¹⁵⁷

¹⁵⁶ Kemmis, S., McTaggart, R. “Participatory Action Research” in Denzin, N., Lincoln, Y., eds., Handbook of Qualitative Research, 2nd ed. (Sage Publications Inc., California, 2000) 567-605 at 590.

¹⁵⁷ Her Majesty’s Stationary Office (H.M.S.O.) Data Protection Act 1998 [Online].

3.5.4.2 Transcribing the Data

Following each interview, the researcher manually transcribed each transcript by listening to the recorded interview whilst typing the words onto a word document on her personal computer. This also enabled her to begin the process of identifying themes. She specifically made notes of all non-linguistic utterances, such as voice intonations, laughter in the conversation, sighs, silences, indignation, anger or emphasis on words, which would have a direct impact on the context of the conversation.¹⁵⁸ By undertaking her own transcribing, this researcher avoided specific errors that can be made by transcribers who might undertake to “help” by altering the data deliberately or accidentally, or missing out essential non-verbal cues.¹⁵⁹

3.5.5 Analysing the Data

3.5.5.1 Step 1 – Read Each Transcript

Twelve months elapsed before the researcher had an opportunity to analyse and code the data. Whilst re-reading the transcripts, she had the opportunity to listen to the individual audio-tape interviews, in order to clarify any meaning. The re-visiting process enabled her to gain familiarity with the data¹⁶⁰

3.5.5.2 Step 2 – Coding the Data

The researcher read the interview transcripts manually, whilst searching for the universal essences of various sorts of matter, including human actions and motives concerned with the ethical themes of freedom, responsibility and choice. There were two reasons for using the manual technique of coding:

¹⁵⁸ Polit, D., Beck, C. Nursing Research: Principles and Methods (2004) 572.

¹⁵⁹ Ibid., 572-573.

¹⁶⁰ Boyle, J. “Field Research: A Collaborative Model for Practice and Research” in Morse, J. ed., Qualitative Nursing Research, 2nd ed., (Sage Publications Inc., Newbury Park, 1991) 273-299 at.285.

1) The researcher wished to immerse herself in the rich data without losing any of the quality which could be lost during a computer programme analysis.¹⁶¹ Since the intention was to present the data as the participants had experienced the phenomenon, codes were generated by searching for key words and indigenous phrases (relevant to nursing) hidden in the data.¹⁶² This process had commenced during the interviews, where patterns began to emerge.¹⁶³

2) The comparatively small number of interviews meant that it was not necessary to use a qualitative analysis computer programme. The manual method of coding gave the researcher the opportunity to reflect on her original analytical judgments, made during the interviews, twelve months previously.

3.5.5.3 Step 3 – The Process of Coding.¹⁶⁴

Eleven transcripts were individually analysed and coded. The analysis of the first transcript yielded fifty-eight codes and the second, a further eleven. In total, one hundred and two codes were identified. Some of these codes were later merged or discarded and forty-nine codes were retained.¹⁶⁵

¹⁶¹ Stern, P. "Are Counting and Coding A Capella Appropriate in Qualitative Research?" in Morse, J., ed., Qualitative Nursing Research, 2nd ed., (Sage Publications, London, 1991) 147-162 at 154.

¹⁶² Ryan, G., Bernard, H. "Techniques to Identify Themes in Qualitative Data." [Online].

¹⁶³ Parahoo, K. Nursing Research: Principles, Process and Issues (1997) 354.

¹⁶⁴ Appendix X - Process of Coding

¹⁶⁵ Appendix XI – Codes and Categories.

3.5.5.4 Step 4 – Clustering the Codes into Categories and Themes

One of the basic techniques for managing the coded data is to cluster the coded data into a set of categories or “piles of similar meaning.”¹⁶⁶ This can be done by developing the categories after the data have been coded or by setting up the categories in advance and then coding the data into the existing categories. If any data fall outside the pre-established categories, other categories can be developed.¹⁶⁷

In order to allow the themes to emerge from the data, the researcher clustered the codes into categories (piles of similar meaning) after the data had been coded. During this process, three themes emerged, one main theme and two sub-themes, and it became apparent that the coded data related to these three themes.¹⁶⁸ It was at this point that the researcher re-visited the taped interviews, to ensure that the themes were relevant and that, as a relatively inexperienced researcher, she was not “over fitting the data.”¹⁶⁹

3.5.6 Ensuring Rigour

In qualitative research, the general consensus among researchers is that a systematic and transparent approach to the process is essential for rigour.¹⁷⁰ There are several strategies to ensure that error is not introduced into the research study and this involves a rigorous process in collecting and analysing the data.¹⁷¹

¹⁶⁶ Parahoo, K. Nursing Research: Principles, Process and Issues (1997) 356; Ryan, G., Bernard, H. “Techniques to Identify Themes in Qualitative Data.” [Online].

¹⁶⁷ Polit, D., Beck, C. Nursing Research: Principles and Methods (2004) 574-575.

¹⁶⁸ Appendix XII - Themes.

¹⁶⁹ Ryan, G., Bernard, H. “Techniques to Identify Themes in Qualitative Data.” [Online].

¹⁷⁰ Rolfe, G. “Validity, Trustworthiness and Rigour: Quality and the Idea of Qualitative Research” Journal of Advanced Nursing [Online] 2006.

¹⁷¹ Macnee, C., McCabe, S. Understanding Nursing Research: Reading and Using Research in Evidence-Based Practice, 2nd. ed., (2008) 170.

Mays and Pope emphasise the need to ensure that there is an appropriate design, that the sampling strategy is clearly described and justified (in this study: 3.5.2.4; 3.5.2.5), that there is evidence of how the fieldwork was undertaken in order to collect the data (3.5.3), that the procedure for data analysis is clearly described and justified (3.5.5), as well as ensuring a well-written and clear report.¹⁷²

Seale and Silvermann point out that there are methods that can be used to address concerns and ensure rigour and validity in recording, analysing and reporting data.¹⁷³

These include the use of audiotapes and videotapes to record data, the use of computer programmes to analyse data systematically and the use of quasi-statistics to support anecdotes in reporting data.¹⁷⁴ In this research study, the researcher adopted the use of audiotapes (where consent was given) to record the interviews and eliminate the potential for systematic bias.¹⁷⁵ Computer software can be used to organise and analyse data in qualitative research, depending on the sample size and the time taken to learn the software programme.¹⁷⁶ The researcher made the decision not to use this method, since it would have taken her some time to learn the software, her sample size was small and she wished to immerse herself personally in the data.

¹⁷² Mays, N., Pope, C. "Qualitative Research: Rigour and Qualitative Research" British Medical Journal [Online] (1995) 311.

¹⁷³ Seale, C., Silverman, D. "Ensuring Rigour in Qualitative Research," European Journal of Public Health (1997) 7 (4) 379-384 at 380.

¹⁷⁴ Ibid.

¹⁷⁵ Rolfe, G. "Validity, Trustworthiness and Rigour: Quality and the Idea of Qualitative Research", Journal of Advanced Nursing [Online] (2006).

¹⁷⁶ Macnee, C., McCabe, S. Understanding Nursing Research: Reading and Using Research in Evidence-Based Practice, 2nd. ed., (2008) 173.

3.5.6.1 Checklist

Since the researcher wished to ensure that every aspect of the research study was considered, she set herself the task of devising a plan of action, with a checklist, to ensure that each step of the research process was covered. The researcher found the use of a “check-list” to be an invaluable tool, which enabled her to set out the research design and procedure systematically, as well as set targets and target dates for completing the research at each stage. This also enabled her to review critically and appraise every decision made at each stage, as well as change the strategy where necessary before moving onto the next stage. In this way, the check-list became a fluid and changing tool through the processes.¹⁷⁷ Furthermore, when gaining ethical clearance for the research study, the researcher developed a “Protocol” (3.5.1.1) to ensure that all aspects of the research were considered and this became a working “check list” to enable the research process.

Barbour states that it is necessary also to ensure that as well as the “check lists,” reminding researchers of the need for a systematic approach to the research (by providing the use of an “aide-mémoire” throughout the research process and data analysis), the rationale and the assumptions for the research method must be thoroughly understood.¹⁷⁸ The goals for this research study were not scientific, but were concerned with clarifying the “means and ends” of moral and ethical decision-making undertaken by nurses at the end of the patient’s life.¹⁷⁹ With this in mind and aided by her

¹⁷⁷ Milne, J., Oberle, K. “Enhancing Rigor in Qualitative Description,” Journal of Wound Ostomy and Continence Nursing (2005) 32 (6) 413-420 at 418.

¹⁷⁸ Barbour, R. “Checklists for Improving Rigour in Qualitative Research: A Case of the Tail Wagging The Dog?” British Medical Journal [Online] (2001), 322.

¹⁷⁹ Burns, N., Groves, S. The Practice of Nursing Research: Conduct, Critique and Utilization, 5th ed., (2005) 62.

“checklist” the researcher used several tools and processes to ensure rigour when collecting and analysing the data.¹⁸⁰

Macnee and McCabe refer to aspects of “trustworthiness, confirmability, transferability and credibility” to ensure the overall quality of the research process.¹⁸¹

3.5.6.2 Trustworthiness

The “trustworthiness” of the data depends on the relationship that the researcher has with the participants so that they feel comfortable with sharing their insights without inhibition.¹⁸² This can be undertaken by spending time in developing a relationship with the participant or formulating a protocol.¹⁸³ Since time was restricted, the possibility of developing an in-depth relationship with the participants was not possible, although time was taken prior to, during and after the interview to develop a relaxed relationship with the participant. In addition, the researcher developed an “Information Sheet” which was given to the participant prior to agreeing to participate in the study, so that an agreement was made between participant and researcher of the type of issues that could be discussed in the interview, if the participant chose to do so.¹⁸⁴ The Information Sheet contained one page with topic details of, “Some of The Issues Related to End-Of-Life Care” and acted as an “aide-memoire” for the researcher to ensure that all the pertinent issues were discussed with the participant.¹⁸⁵ Trustworthiness in the research process can be further developed if there is an “audit trail” to track and verify the process, thus

¹⁸⁰ Macnee, C., McCabe, S. Understanding Nursing Research: Reading and Using Research in Evidence-Based Practice, 2nd. ed., (2008) 170.

¹⁸¹ Ibid., 170-173.

¹⁸² Ibid. 170.

¹⁸³ Ibid. 170.

¹⁸⁴ Appendix IV - Information Sheet.

¹⁸⁵ Kirk, S. “The Value of Qualitative Research,” The Value of Qualitative Research (Online) (2009).

confirming that the data were generated through a consistent and reliable strategy (see 3.5.6.5.3).

3.5.6.3 Validity

Milne and Oberle state that strategies to ensure that rigour has been applied to the qualitative research method can include “authenticity, credibility, criticality as well as integrity of the researcher.”¹⁸⁶ Although some researchers are sceptical of the positivists’ notion that “validity” can be achieved by the rigorous application of strategies, validity is a way of measuring the accuracy or the truth of the overall research design and process and whether the explanation is credible.¹⁸⁷

3.5.6.3.1 Credibility

Internal validity or “credibility” can be a positive means of judging whether the research descriptions and explanations accurately reflect the experience of the participants. Some researchers suggest that the ideal situation is to determine this through “member-checking” where, once the interviews have been analysed, the findings are returned to the participants, who then recognise the findings as being true to their experience.¹⁸⁸ However, not all researchers agree that “member checking” is useful, since “meaning and understanding are open to interpretation over time” and the participants may not be

¹⁸⁶ Milne, J., Oberle, K. “Enhancing Rigor in Qualitative Description,” Journal of Wound Ostomy and Continence Nursing (2005) 32 (6) 413-420 at 415.

¹⁸⁷ Rolfe, G. “Validity, Trustworthiness and Rigour: Quality and the Idea of Qualitative Research”, Journal of Advanced Nursing [Online] (2006); Carter, D., Porter, S. “Validity and Reliability” in Cormack, D., ed. The Research Process in Nursing, 4th ed., (Blackwell Science, Oxford, 2000) 29-50 at 30; Janesick, V. “The Choreography of Qualitative Research Design” In Denzin, N., Lincoln, Y., eds., Handbook of Qualitative Research, 2nd ed. (2000) 379-399 at 393.

¹⁸⁸ Streubert, H., Carpenter, D. Qualitative Research in Nursing: Advancing the Humanistic Imperative (1999) 29; Macnee, C., McCabe, S. Understanding Nursing Research: Reading and Using Research in Evidence-Based Practice, 2nd. ed., (2008) 172.

the best people to judge what is valid research.¹⁸⁹ There may be many reasons why participants deny recognition of the findings, including the rejection of attitudes that are attributable to some participants but not acceptable to others.¹⁹⁰

In this research study, the researcher perceived difficulties with the strategy of returning the data to the participants after analyses for the following reasons: (1) due to the nature of the research, the findings did not represent the individual subjective experiences of each participant, but represented examples of all the participants' experiences in order to reflect on those experiences as a whole; (2) the research would be categorised into themes and codes and a participant may not recognise any particular part of the emergent themes and categories as their individual understanding of their world.¹⁹¹

To overcome some of the limitations, the researcher focused on involving the participants in verification of content.¹⁹² The researcher used a "data validation process" where she returned the data to the participants in order to give them the opportunity to clarify any part of the data or to discuss with the researcher any part of the data that may contain the researcher's own prejudices.¹⁹³ This ensured that the transcripts were an accurate transcription of the conversation and verified as authentic. Furthermore when presenting the findings, she used quotes from the transcripts to allow the reader to hear

¹⁸⁹ Tuckett, A. "Part II. Rigour in Qualitative Research: Complexities and Solutions," Nurse Researcher (2005) 13 (1) 29-42 at 35-36.

¹⁹⁰ Carter, D., Porter, S. "Validity and Reliability" In Cormack, D., ed. The Research Process in Nursing, 4th ed., (2000) 29-50 at 38-39.

¹⁹¹ *Ibid.*, 38.

¹⁹² Tuckett, A. "Part II. Rigour in Qualitative Research: Complexities and Solutions," Nurse Researcher (2005) 13 (1) 29-42 at 36.

¹⁹³ Parahoo, K. Nursing Research: Principles, Process and Issues (1997) 292.

the “voice” of the researcher and the “voice” of the participant (known as “thick text.”) thus further verifying the content.¹⁹⁴

3.5.6.3.2 Transferability

External validity or “transferability,” can confirm whether the findings of the study can be applied to different groups or in different settings, thus ensuring that the sample selected was representative of the population, a process which was not used in this study, since the sampling strategy was not designed to guarantee that the participants were representative of the population.¹⁹⁵ Another group in another area may have produced different results. However, when the researcher discussed informally the findings with other nurses (external checks), the themes emerging had resonance with them and their experiences, which would appear to imply that they could be transferred to other settings.¹⁹⁶

3.5.6.4 Criticality: Researcher Integrity and Reflexive Thought

Within the research interview, the researcher undertook her own process of “reflexive thought” where she critically thought through the interaction between herself and the participant.¹⁹⁷ The researcher had been aware of her different identities, that of being an “insider,” of being very much at home in the care home environment, but also one of being an “outsider,” as being “the manager” or “regional manager” when managing care

¹⁹⁴ Pontin, D. “Interview” In Cormack, D. ed., The Research Process in Nursing, 4th ed. (2000) 289-299 at 295; Jasper, M. “Issues In Phenomenology for Researchers of Nursing,” Journal of Advanced Nursing (1994) 19; 309-314 at 311.

¹⁹⁵ Macnee, C., McCabe, S. Understanding Nursing Research: Reading and Using Research in Evidence-Based Practice, 2nd. ed., (2008) 171-172.

¹⁹⁶ Ibid. 172.

¹⁹⁷ McNair, R., Taft, A., Hegarty, K. “Debate,” BMC Medical Research Methodology [Online] (2008) 8:73.

homes, which removed her from the “front-line.”¹⁹⁸ In addition, she was now a lecturer in nursing, an “outsider” to the participant and no longer part of the care home environment.¹⁹⁹ Reflexively acknowledging her pre-existing assumptions, especially that of being an “insider” with insider knowledge, was an important process, for it enabled her not to assume similarities in experience with the participant.²⁰⁰

During this process she also reflected on her own personal feelings, her experiences and how they might influence the “dynamic interaction” between herself and the data and the data analysis process, which might not then reflect the true experiences of the participants.²⁰¹

However, reflexive thought and knowledge of self had been a process that she had been required to embrace since her time as a student of mental health nursing and one that she used throughout her career, so she felt confident that she had exercised this process effectively and was satisfied that she had used appropriate strategies, to ensure that error was not introduced into the research study.²⁰² The use of “reciprocity” is one reflexive tool where the researcher shares her “feelings and experiences with the participant” which then enhances rapport between researcher and participant.²⁰³ By using this approach, the researcher found that this encouraged openness in the interview and also

¹⁹⁸ Ibid.

¹⁹⁹ Ibid.

²⁰⁰ Ibid.

²⁰¹ Burns, N., Groves, S. The Practice of Nursing Research: Conduct, Critique and Utilization, 5th ed., (2005) 538-539.

²⁰² Macnee, C., McCabe, S. Understanding Nursing Research: Reading and Using Research in Evidence-Based Practice, 2nd. ed., (2008) 170.

²⁰³ McNair, R., Taft, A., Hegarty, K. “Debate,” BMC Medical Research Methodology [Online] (2008) 8:73.

encouraged the participant to reflect on her own experiences.²⁰⁴ This was extremely rewarding and interesting, and beneficial for the research.²⁰⁵

3.5.6.5 Confirmability

In this research, “confirmability” was, therefore, undertaken by the consistent strategy used to recruit participants (3.5.2), to collect the data (3.5.3), to analyse and organise the data into codes and themes (3.5.5). Since the researcher and participants agreed not to meet after the second interview, unless they chose to contact her, she felt assured that the participants had confidence in her integrity and good practice and that her interpretation of the research would be open and truthful.²⁰⁶

By ensuring that the participants had the opportunity to present their views freely, as well as ensuring that those views were accurately represented through the transcribing, analysing, and coding and verification processes, the researcher felt assured that she had presented a true and authentic portrayal of the participants’ viewpoints.²⁰⁷ Detailed description of each strategy is included in this chapter and, as stated, the data analysis and coding process is included in appendices.²⁰⁸ This allows any reader to decide whether the researcher’s interpretation of the data was a reasonable one.²⁰⁹ The participants have been contacted by letter on a regular basis throughout the research process and will be informed when the research is concluded. At the end of the study, each participant will be given a copy of the research thesis. The findings of the research

²⁰⁴ Ibid.

²⁰⁵ Ibid.

²⁰⁶ Ibid., 39.

²⁰⁷ Milne, J., Oberle, K. “Enhancing Rigor in Qualitative Description,” Journal of Wound Ostomy and Continence Nursing (2005) 32 (6) 413-420 at 415.

²⁰⁸ Appendices X, XI, XII - Data Analysis and Coding.

²⁰⁹ Carter, D., Porter, S. “Validity And Reliability” in Cormack, D., ed. The Research Process in Nursing, 4th ed., (2000) 29-50 at 39.

will be distributed throughout the nursing community through conference presentations, which allow for verbal feedback confirming or denying the results, as well as peer-reviewed publications.

3.5.6.5.1 Peer Debriefing

In order to enhance rigour during the research study, the researcher submitted three of her interviews to her academic supervisor, who read and coded them “blind”; they then compared their results and discussed in full any discrepancies. These discussions were extremely useful during the analysis and coding phase, which resulted in the generation of new categories or others being sub-merged.²¹⁰ Even though there is some contention that peers can never be as involved or immersed in the data in the same way that the researcher is, peer debriefing does enable bias to be detected and avoids the pitfall of the researcher attempting to “fit interpretations that cannot be substantiated by the data.”²¹¹

3.5.6.5.2 Deviant Case Analysis

It is also important that the findings are plausible and that the anecdotal evidence does not only include the researcher’s preferences.²¹² One valid method for eliciting variation in qualitative research is the system of selecting “negative” or “deviant” cases.²¹³ This means that the researcher is deliberately seeking out examples where participants

²¹⁰ Ingleton, C., Seymour, J. “Analysing Qualitative Data: Examples from Two Studies of End-of-Life-Care”, International Journal of Palliative Nursing (2001) 7 (5) 227-233 at 232.

²¹¹ McBrien, B. “Evidence-Based Care: Enhancing the Rigour of a Qualitative Study,” British Journal of Nursing (2008) 17 (20) 1286-1289 at 1287.

²¹² Seale, C., Silverman, D. “Ensuring Rigour in Qualitative Research,” European Journal of Public Health (1997) 7 (4) 379-384 at 380.

²¹³ Morse, J. “Strategies for Sampling” in Morse, J. ed. Qualitative Nursing Research, 2nd ed., (1991) 127-146 at 128; Ryan, G., Bernard, H. “Data Management and Analysis Method” In, Denzin, N., Lincoln, Y., eds. Handbook of Qualitative Research, 2nd ed. (Sage Publications Ltd., Thousand Oaks, 2000) 769-802 at 782.

deviate from the majority viewpoint. This was achieved by using a systematic coding scheme, which made it possible to conduct deviant case analysis. For example, during the analysis phase, the researcher realised that participant six deviated from the norm when discussing “Relative or Friend Participation in Decision-Making.” Whilst ten participants stated that they would negotiate with the relatives on matters concerning pain relief, participant six held the position that there was no room for negotiation and that the relative’s wishes were always the priority. The researcher presented her statement in the findings.

“....I won’t go against a relative. It’s their father, their mother, not mine.”

Another example is where the researcher discussed “Nurses’ Belief Systems” with the participants. During the interview and analysis phase she realised that ten participants held a spiritual belief of some form, which helped to support them through the patient’s end-of-life care. However, participant eight deviated from the norm stating,

“....I am a secular person. So I tend to make my judgments more on a logical basis. I don’t have that baggage as it were, believing in higher powers and things like that.....”

This statement was also presented in the findings. By seeking out instances in the data that deviate from the norm and by presenting these in the findings, the reader is then reassured that the reporting of the data is plausible and does not focus only on those that support the researcher’s preferences.²¹⁴

²¹⁴ Seale, C., Silverman, D. “Ensuring Rigour in Qualitative Research,” European Journal of Public Health (1997) 7 (4) 379-384 at 380.

3.5.6.5.3 Audit-Trail

As further confirmation that the data are trustworthy and valid, an “audit trail” requires that the research study is audited to eliminate the possibility of bias.²¹⁵ However, Cutcliffe and McKenna argue that there is always bias in the various decisions made on literature, choice of setting and selection of participants and detecting bias in qualitative research does not necessarily indicate a limitation of the study.²¹⁶ In this study, bias was used as a positive tool in the sampling process (3.5.2.4).

Auditing requires that the researcher stores all raw data for review if required, however, in this research study, not all raw data would be available for scrutiny.²¹⁷ The researcher guaranteed confidentiality to her participants and, since the audio-tapes were the confidential and personal property of the participants (in order to remove the possibility of voice recognition), they would be returned to them and destroyed in the presence of the researcher on finalisation of the research study. However, to enable a partial auditing process, the transcribed data were retained. In addition, the process of analysing and coding the data are available in the appendices and open to scrutiny.²¹⁸ This ensured that the research process was logical and traceable.²¹⁹

3.6 Conclusion

In order to answer the research question, the researcher undertook a qualitative interview based study, with eleven participants, to explore how nurses made decisions on

²¹⁵ Cutcliffe, J., McKenna, H. “Expert Qualitative Researchers and the Use of Audit Trails,” *Journal of Advanced Nursing* (2004) 45 (2) 126-133 at 130.

²¹⁶ Ibid., 130.

²¹⁷ Burns, N., Groves, S. *The Practice of Nursing Research: Conduct, Critique and Utilization*, 5th ed., (2005) 539.

²¹⁸ Ibid. 539.

²¹⁹ McBrien, B. “Evidence-Based Care: Enhancing the Rigour of a Qualitative Study,” *British Journal of Nursing* (2008) 17 (20) 1286-1289 at 1287.

end-of-life care, within private care homes. By doing so, she discovered many factors related to the phenomenon. In chapter four the researcher will present the findings from the qualitative investigation.

CHAPTER FOUR
A PRESENTATION OF THE FINDINGS
FROM THE QUALITATIVE INVESTIGATION

4.1 Introduction

By investigating how nurses make decisions on end-of-life care, three themes that characterised the nurses' experiences emerged from the qualitative investigation. These have been consolidated for the purpose of this discussion and each theme and its individual categories can be viewed in Appendix XII.

Major Theme

- I. Caring for the relatives and staff whilst ensuring the patients' needs are met and that they die in peace surrounded by love.

Sub-Themes

- II. Nurses' responsibilities to ensure that the patients have adequate hydration and nutrition during the dying process.
- III. Nurses being the advocates to ensure that medication is appropriate and meets the needs of the patients.

The findings are presented within the eight categories identified and labelled during the research analysis process. These are: (1) "The Dying Process", (2) "Spirituality", (3) "Nurses' Professional Decision-making", (4) "Emotions", (5) "Duty to a Patient", (6) "Patient's Rights", (7) "Difficulties", (8) "Support".

4.2 Categories

In this chapter the researcher will divert from the normal chapter numbering format and present the categories in the exact same numerical format as presented in Appendix XII. However, in order to make these clear to the reader, the numbers will be placed in brackets.

4.3 (1) The Dying Process:

4.3 (1.1) Nurses' Views on The Dying Process

Caring for patients in a care home means that nurses work in a community setting but are entering the domains of the patient's own home. In some care homes there may be a small unit to facilitate the care of the dying.

Researcher

How do you see the dying process, in general, with the elderly?

Nurse (Participant Four)

A natural death is the best kind of death, but this is not always possible. Dying on your own would be the worst kind of death, I would personally hate this, but in the home, if the relatives are not there, then we ensure that a Care Assistant is there to sit with the patients. We have a key worker system and the key worker, the care assistant, comes in in their own time, to stay with the dying person. One key worker arranged a rota of staff to be with this one man because the relatives were abroad. It is difficult when this happens, as it is difficult to know when to call the relatives. One relative arrived in the country, but as she arrived, her mum died, so she never did see her mum alive again. However, the key worker, in this case, had a close relationship with the relative and the relative felt happy that everything had been done for the mother and that the mother had died in the presence of familiar faces, that is, the staff.

Nurses viewed the end of the patient's life as complex, requiring expert negotiating skills to liaise with patients, their relatives, doctors and other staff.¹

4.3 (1.2) Patients Knowing They Are Going To Die

It was important for both patients and relatives, that nurses “be there” and enable the dying process without fear.² Participant three noticed that some relatives found it difficult to come to terms with the reality that the patient was dying and became extremely anxious.

Participant five observed that some patients became very serene just before they died, as if they knew that “their time had come.”³ This was especially so with patients with dementia, who could not vocalise their feelings, but began to withdraw into themselves, refusing food, as if they knew they were going to die.⁴ Participant Seven related that some patients did not want to die alone and in many ways were unprepared for death, whilst others accepted that they were going to die and had proactively prepared for their funeral.

Nurse (Participant Seven)

We have people in here who have arranged their funeral, their hymns, what kind of service they want, what the family have to wear, that they don't want any flowers because they know that their family will not be strong enough to do it, so they do all this, and it's a case of they either write it down or one of the staff writes it for them.

¹ Participant Four, Six, Seven.

² Participant Four.

³ Participant Five.

⁴ Participant Eight.

The nurses' experiences were that the patient's mental and physical state greatly influenced their process of dying and participant six reflected that, in general, patients were aware of their impending death and nurses tried to alleviate their concerns and give them support to die peacefully.

4.3 (1.3) Patient's Mental State

Participant one stated that, in her experience, some patients suffered mentally from fear of dying and loneliness. For participant three, this was especially so with those patients diagnosed with dementia.

Researcher

Have you experienced patients going through mental suffering?

Nurse (Participant Three)

Yes, there was one lady that I remember, she had dementia and she was mentally scared, I saw it in her eyes.

Researcher

How did you feel?

Nurse

I felt sad, sorry, I couldn't really do anything to help her, to reach out to her except touch her, cradle her in my arms, talk to her, make her feel safe, reassure her. It is difficult with dementia where people probably have a fear of the unknown, they don't know what is happening, but if they do, they may feel that they don't know where they are going. It's really sad.

Some nurses noticed that patients became discouraged with living, especially those with chronic illness, and they considered fatigue and the inability to overcome it as a

disabling experience, often associated with pain, which interfered with the patient's ability to function normally.⁵

Researcher

What if the resident says, "Just do away with me" and that can be said as a joke; or do you think they mean it?

Nurse (Participant Six)

Oh they do mean it, I used to sit and have a chat and try and find out, that is if they are able to communicate, what makes them say that, or why they have said it; if there is anything I can do to make them feel better about themselves or better about the situation or what's bothering them, or what resources can be brought in to make them feel better; maybe it is depression, maybe they need medication to brighten them up..... they often say, "well what is there to live for?" I point out the good things around: the family, the grandchildren I see around regularly, you know, we look after you and we love you as we should and point out the good things outside and have a look at the garden at the nice things around..... I think they just get fed up with being cooped up maybe of not being able to do as they want to do.....

4.3 (1.4) Patient's Physical Pain

Participant three described one mentally alert, intelligent, eighty-eight year old lady whose condition was deteriorating rapidly and who stated that all she wanted was to be pain free. Although the patient was exhausted, patient three felt that since she had been a very independent lady, it was important that the increased care input "was given subtly." Within the context of the conversation the researcher understood this to mean a caring, gentle response to protect the patient's independence.

⁵ Participants One, Two, Six.

If the patient were able to take medication orally, the nurses would give oral pain relief, but otherwise, Fentanyl Patches⁶ would be used or a morphine syringe driver to give pain relieving medication subcutaneously.⁷

Participant seven stated that, if the resident was in a lot of pain at the end stages of life, the focus would be on alleviating pain; however, all aspects of the patient's care, including the family's well-being was considered. Participant five thought that sometimes hydrating the patient made him more comfortable, although she added that there were several articles on the subject as to whether this was of benefit or not.

4.3 (1.5) Relative or Friend Participation in Decision-Making

The nurses regarded a good relationship with the relatives as a positive factor in caring for the patient. Participant three felt that nurses knew the patients better than the relatives, but she and participant eight considered that it was generally accepted that relatives should be included in the decision-making process wherever possible. Two examples would be when to keep the patient in the care home or move him to the hospital,⁸ or whether to give further medical intervention or withdraw antibiotics.⁹ Relatives were also involved in decisions with regard to the patient's medication¹⁰ or where the patient was unable to give consent.¹¹ Although the nurses acknowledged that

⁶ Participant Nine.

⁷ Participants Two, Five, Eight.

⁸ Participant One.

⁹ Participant Two.

¹⁰ Participant Six.

¹¹ Participant Five.

relatives should participate in the decision-making process, they felt it was important to “get to know the families” before adhering to their wishes.¹²

At times, the nurses experienced difficulties in communicating to the relatives, their views on how they felt the patient should be cared for at the end of life, especially where the relatives requested aggressive treatment.¹³ On one occasion, against the recommendations of the nurses but instigated by the relatives and doctor, an elderly lady of ninety-seven years was sent to hospital to undergo multiple investigations. The patient died the next day in hospital, separated from familiar surroundings and people. This had a profound effect on the nursing staff and they felt very sad at the outcome.¹⁴

Before any decision was made on whether or not to continue hydration and nutrition, relatives were consulted and the possible outcomes discussed. However, even where a subcutaneous infusion could be given, the patient would be deprived of hydration, if that was what the relatives requested.¹⁵

Researcher

Does the subcutaneous drip make any difference as far as comfort is concerned?

Nurse (Participant Seven)

I think in a way, although they are not getting a huge amount of fluid, perhaps it is just enough to keep them comfortable. It lets the family see that it is just not a case of “Oh they’re dying, there is nothing else we can do.” But at the end of the day, if the family comes in and says, “I don’t want this done” or the patient themselves might say, “I don’t want a drip up if that’s O.K.,” then that’s fine.

¹² Participant Two.

¹³ Participants Two, Five.

¹⁴ Participant Five.

¹⁵ Participant Seven.

Participant eight found that relatives did not always agree with each other on what was the best care for the patient, thus causing difficulty for the nursing staff as they tried to cope with the unreasonable demands of a divided family. The majority of nurses were content with the relationship with the relatives and were satisfied that they should be involved in the decision-making process.¹⁶

4.3 (1.6) Relationships

The relationship between staff and patient often extended beyond the confines of duty and it was not unusual for the care staff to do extra things for the patient, for example, going to a local food shop to buy the patient's favourite food if the care home food did not satisfy him.¹⁷

In order to cope with what could be a sad subject, humour was perceived as being essential to both nurse and patient, when making plans for the end of the patient's life.

Researcher

Do they ever ask what is going to happen to them, after they die?

Nurse (Participant Five)

Some of them do when they are well. We've got one lady who is going to give her body to medical research. She often jokes about that. I have another lady who heard that there was a private funeral. Another resident had died and had had a private funeral and she said, "I think I will do that." So I said, "None of us will be able to come and wave you off" and she said, "Well, would you want to?" I said, "We've known each other for quite a while now, I would perhaps want to come and say a couple of goodbyes." She said, "Oh alright then, I'll put you on my list of invitations." (Laughter).

¹⁶ Participants One, Two, Four, Five, Six, Seven, Eight, Nine, Eleven.

¹⁷ Participant One.

In addition, it was the close relationship between relative and staff, and the nurses' compassion and understanding,¹⁸ which enabled relatives to communicate freely with them, especially when they required extra support as the patient's condition deteriorated.¹⁹ Participant nine selected the carers who were most liked by the family, recognising the benefit to the patient if there was a good bond between carer, patient and relative.

Participant one perceived trust between relatives and staff as important; however, if there was disagreement on care especially with regard to pain relief, it caused difficulties within the relationship. At that point, the patient's general practitioner (G.P.) would normally be involved in the discussion, in order to facilitate a compromise in care.

Researcher

What is your relationship with the G.P.s?

Nurse (Participant Four)

It is very good. The doctors listen to the nurses and they also speak to the family. They consider both points of view. With regard to nursing care, it is the nurses who have the final decision. For example, the nurses will decide whether to administer the medication or not. The doctors tend not to give fluids, especially if someone had a stroke, but he would ask my opinion.

According to one nurse, nurses developed an "intimate relationship"²⁰ with each other and this close relationship helped them through difficulties in caring for the dying patient.²¹

¹⁸ Participant Six.

¹⁹ Participant One.

²⁰ Participant One.

²¹ Participants Seven, Eleven.

Nurse (Participant Eleven)

Well we were just saying yesterday when one of our residents died and the carers were relating how they washed her and dressed her after she died when one of the carers said, "I just couldn't do it, I just couldn't do it. It is just so upsetting for me, I just cannot do it." So I said, "That's O.K." Some get really upset and they really sob.

Researcher

Why are they upset?

Nurse

Well, because they have grown fond of them. They have worked with them. They build a relationship and I suppose they relate it to, if it was like one member of their family, they would feel the same.

4.3 (1.7) Suffering

According to some of the nurses, relatives appeared to suffer when the patient died, often a process that began when they realised that they could no longer care for the patient and had to admit him or her to a care home. They also suffered when the patient became incapacitated, not understanding fully what was happening to their loved one.

Researcher

Do you think that relatives suffer?

Nurse (Participant Three)

Yes, I think relatives suffer because they see their relative in a different way to what we see them. They may see this person who needs everything done for them, who may be drooling when they are fed and they suffer because they don't really understand what is happening to that loved one. It is difficult for them.

Researcher

What about mental suffering for the resident, the relative, you; does it exist?

Nurse (Participant Five)

Definitely. I think we see more of the relatives' suffering than we do the actual client suffering. The client receives treatment to ease and hopefully stop pain and other symptoms, but we can't give drugs to the relatives.

Researcher

How do they express that? How do you know?

Nurse

Sometimes it is by being anxious and nitpicking about the problems and sometimes they can't face seeing their relative dying, but they are reluctant to visit. Mostly, it is "oh my goodness, how long are they going to hang on for?"

Often relatives continually asked questions about the patient's time of death and nurses attributed this to mental suffering.²² This expressed itself through, anxious facial expressions and unusual behaviour interpreted as indicating feelings of guilt, for not having cared for the patient to the end of his life.²³ If they had been given a specific day or accurate time of the patient's impending death, this may have enabled them to cope.

Participant eight noticed that relatives experienced a sense of relief when a patient with dementia died, acknowledging that theirs and the patient's suffering was coming to an end. They seemed to experience two deaths, the first, when they lost the person through dementia and the second when the patient physically died.²⁴ Staff also suffered when residents died, experiencing a profound sense of loss that was akin to losing a friend.²⁵

²² Participants Seven, Ten.

²³ Participant Eleven.

²⁴ Participant Eight.

²⁵ Participant Eight.

4.3 (1.8) Traditions/Rituals

Nurses have their own way of coping with death and their suffering could be alleviated by the traditional ways of saying goodbye and their own individual strategies of coping with the patient's death.

Nurse (Participant Four)

.....Rituals after death are very important because it shows our last respect for that person. This helps the staff and it also helps relatives who are upset when they see the respect that is given to their loved one. For us it is a job complete. The staff go to the funeral, often in their own time. This gives completion and is important because it is the final chapter in that person's life and the staff let go. They go onto the next person after the final goodbye. It is important to say goodbye because we need to move on quickly. We couldn't constantly live with death.

Participant seven did not "like the dead person's face covered" and whilst washing and dressing his body, she talked to him as if he were still alive. In addition to leaving a light on in the room, she always opened the window to "let the spirit out."

4.3 Summary

The nurses' main concern was to ensure that the patient died in peace, free from pain and without physical or mental suffering. Relationships with relatives and doctors were founded and decisions made on a professional basis, the patient/nurse relationship was more intimate, that of friend and nurses suffered when the patient died.

4.4 (2) Spirituality

4.4 (2.1) Spirituality, Religion.

Participants four and six found that those patients with a religious belief appeared to be peaceful at the end of their lives in the knowledge that they were "going to a better

place,” but to others, everything “seemed worse at night” and they appeared frightened, had difficulty in sleeping and did not want to be left alone. According to them, they were the ones who feared “what might be on the other side.”

Participant five said, that one of her patients, a Roman Catholic, requested a visit from a priest so that she could receive the last rites. She noticed that the priest returned to visit the patient several times and thought this might be to ensure that the patient was at peace. Where the patient had dementia and the nurse considered bringing in a minister or priest to administer spiritual care, the relatives were first consulted.²⁶

4.4 (2.2) Nurses' Belief Systems

The nurses' belief systems helped to support them through the patient's end-of-life care in several ways. Participant three stated that it was her own Christian perspective, as well as training and experience, which underpinned her views on dying and death. Participant four had no specific beliefs, but felt that the important task was to comfort the patient and the family. Participant six consoled herself with the fact that “God gives life and God takes away life.” She could accept the patient's death because, in her opinion, it was the right time for the patient to die. This was similar to the beliefs of participant ten who believed there was “comfort and solace to be found in God.” Participant eleven liked to think that there was something after death and that life continued on to something better, whilst participant twelve believed in reincarnation and, therefore, was satisfied about continuity after death.

²⁶ Participant Three.

Participant five thought that there “was some power out there” and that there was something that lingered and then went on somewhere else, but she did not know what it was. However, participant eight took an entirely different view and did not have a particular belief system that might influence her judgments on care.

Nurse (Participant Eight)

..... I am a secular person. So, I tend to make my judgments more on a logical basis. I don't have that baggage as it were, believing in higher powers and things like that. [Apologises to researcher in case she sounds insulting. Reassured by researcher that she did not]. I concentrate solely on the patient, their physical and emotional needs and nothing else. As I say I make logical decisions, but it doesn't mean that I don't aim for the best.

4.4 (2.3) Ethos

Participant six perceived that the caring attitude contributed to their care home having a distinctive character that enhanced end-of-life care. Individual past experiences moulded and shaped the nurses' caring attitudes, thus forming the basis of a nurturing community. Participant five thought that in many ways, the home was an extension of the community, where staff, families and patients all lived together. She had grown up in a small town and thought that the ethos of the home was due to families intermingling with staff on an informal basis, because they knew each other well.

Researcher

When you talked about the ethos, you having an ethos which you apply to your work where does that come from. Is it your upbringing, does it come from your training, is it knowledge that you have developed?

Nurse (Participant Five)

It all comes together and grows togetherin the expectations of life, and how you've been treated in the past and how you have seen other people being treated, how you would like to be treated yourself. Just going on from there and as you gain

more knowledge you can just put stuff into that. I grew up in a small town where my parents were quite well known and if I said my name, they would say, “your xxx’s daughter, aren’t you?” and I would say “Yes.” My grandparents all lived close by and so they were cared for by the family mostly. They did go into hospital for respite and they did die in hospital, but a lot of the care in the interim bit was done with the family and I used to go home to help my mother look after them. I think it is just growing older and as you become older as well you start to think well, this could be me, this could be my mum, it’s not just my grandfather, this could be my mum. I would hate to think my parents were somewhere not being looked after as well as I would expect them to.

4.4 Summary

The nurses’ belief systems, some founded in their spirituality and others from a secular viewpoint, formed and shaped through their experiences, contributed to the caring ethos of the home and shaped their views on end-of-life care.

4.5 (3) Nurses’ Professional Decision-Making

4.5 (3.1) Nurses’ Decision-Making

Participant three considered that there were many factors, such as “knowing the resident well,” Christian perspectives, training and the quality of the patient’s life which contributed to how nurses make decisions and which impact on their personal feelings and professional accountability.

Some nurses acknowledged that their many years of experience underpinned their decision-making process,²⁷ whilst others relied on input from the patient’s relatives.²⁸ They felt it was important that the family were content with the patient’s care,

²⁷ Participants One, Two, Three, Seven, Ten, Eleven.

²⁸ Participants Two, Four, Five, Six, Nine.

especially where decisions were to be made on whether they should remain in the home or be admitted to hospital.

Decisions, especially with regard to pain control, were made based on information given to the nurse by the care assistants, who would inform the nurse of a change in the patient's condition.²⁹

4.5 (3.2) Nurse's Role

At the end of the patient's life the nurses perceived part of their role as "helping the person to find peace,"³⁰ reassuring the patient³¹ and caring for the relatives.³² In addition, they recognised that part of their role was to facilitate the services of external agencies such as the minister,³³ or provide practical help such as providing the relatives with sleeping accommodation, whilst sustaining them with tea and sandwiches.³⁴

For one nurse, it did not matter whether the patient was "difficult" or otherwise, since she was taught in her training school that "a nurse should be unbiased, care for and nurse everyone." She said, "I think that's what a nurse is, to nurse beings, to nurse persons."³⁵

²⁹ Participant Five.

³⁰ Participant Four.

³¹ Participant Seven.

³² Participant Five.

³³ Participant Four.

³⁴ Participant Five.

³⁵ Participant Nine.

4.5 (3.3) Knowledge

It was not always obvious that death was imminent, but several nurses described a feeling of “knowing” when the patient was going to die.³⁶ It was this knowledge that helped them to make decisions about whether to send the patients to hospital or keep them in the care home to die. Also knowing the patient’s likes and dislikes helped the nurses care for them. One nurse regarded knowledge as something that she had gained over the years and this assisted her in interpreting the patient’s body language to ensure that she provided the best care for him/her.³⁷ Another nurse relied on her life experience, as well as her knowledge and experience of animals, to understand when a patient was “struggling.”³⁸

Knowledge was acquired through several avenues, such as, life and professional experience, learning from others, continual practice and continuing education. However, participant one acknowledged that “learning from others” was not necessarily recommended, since it was possible to acquire poor knowledge as well as rich knowledge.

Nurse (Participant One)

I think that when you are caring for the dying, I think that you learn a lot from other staff and I think that learning from other staff....what you are learning can be bad things as well and you can learn from that.

Knowledge could also be acquired by reading professional nursing journals and this was used to persuade a doctor to treat an eighty-three year old lady who had suffered a

³⁶ Participant One, Three, Four, Ten.

³⁷ Participant Five.

cerebral vascular accident (a stroke).³⁹ The nurse “knew” that the patient would recover just as she “knew” that some patients would not recover. Life experience, a feeling of knowing, nursing experience and training, all contributed to the nurses’ experiences of knowing that someone was going to die. This was viewed as a positive tool to assist the nurses in making the best decisions for their patients.⁴⁰

Researcher

So when you see someone who is dying, are your feelings based on an accumulation of knowledge and instinct, or something else?

Nurse (Participant Six)

You get a feeling, you know. I don’t know how to explain it. You know by the look in their eyes, the thready pulse, the breathing changes; you just know within yourself that the time is coming.

Their knowledge also helped them prepare the relatives and staff for the patient’s impending death and gave them the opportunity to ensure that the patient was at peace, free from pain and any form of mental or physical suffering.

4.5 (3.4) Intuition

However, some nurses found it difficult to describe how they acquired their knowledge stating that much of what they did was instinctive⁴¹ and that some people just had “gut instincts” and were tuned to those gut instincts.⁴² One nurse described a carer as being the “slightly witchy type” because she appeared to know when people were suffering. However, she did concede that the carer also had a great deal of experience and that that

³⁸ Participant Eleven.

³⁹ Participant Six.

⁴⁰ Participant Ten.

⁴¹ Participant One.

⁴² Participant Ten.

was probably the reason for her knowledge.⁴³ Another nurse considered that her intuitive knowledge was essential to understanding the needs of the patient, so that she could communicate the information to the doctor, in order to receive the best care for her patient.⁴⁴

Researcher

When you are looking after the elderly and they are dying, what would you say was the most important quality for a nurse to have?

Nurse (Participant Three)

Time and patience (pause). There are a lot of elderly people with end stage dementias and they are not really able to voice things; acting as an advocate and using your intuition. You know, all the knowledge that you have gained over the years to interpret the person's body language so that you can then act as an advocate and pass things on to get the best treatment that you can from the G.P.

When employing suitable carers, participant eight stated that she measured the suitability of the candidate by "something you sense" and "not something you can put your finger on." Participant eleven used instinct to measure the patient's pain.

Researcher

What do you call pain and what do you call uncomfortable?

Nurse (Participant Eleven)

It is difficult to say. I think as a nurse, you just have an instinct, you just get to know if somebody, well I do, I don't know how you feel, but you just get to know if somebody is uncomfortable, you can tell by their eyes, by their posture, you can just tell.

⁴³ Participant Ten.

⁴⁴ Participant Three.

4.5 (3.5) Assessment

Nurses relied on the patient's physical signs such as grimacing, or hands clenched, when assessing the patient to determine what was required. They also considered feedback from colleagues as important to confirm that accuracy in assessing the patient and "doing the right thing."⁴⁵ Participant two made an overall assessment of the whole situation when caring for someone who was dying, including, the relatives and staff in the care home.

Where decisions were made on whether or not to give medication, some nurses depended on their professional experience to assess the patient.⁴⁶ If the patient were conscious, one nurse stated that she would assess the level of pain by using a pain assessment tool.⁴⁷

Where the patient had dementia, participant nine would rely on the patient's facial expressions to make an assessment of the level of his pain.⁴⁸ Where the patient was unconscious, nurses found it difficult to assess the patient. One nurse noticed that "restlessness and agitation" could be a sign of the patient experiencing pain.⁴⁹

Whilst working in a care home outside the U.K., participant six drew from her professional experience to assess a patient with an infection, who was in danger of not

⁴⁵ Participant One.

⁴⁶ Participants Two, Six, Eight, Ten.

⁴⁷ Participant Eight.

⁴⁸ Participant Nine

⁴⁹ Participant One

being treated by a doctor. She insisted that the patient could respond to treatment and should be given the appropriate treatment. By doing so she saved the patient's life:⁵⁰

Researcher

Have you ever had a conflict about that duty of care with the doctors?

Nurse (Participant Six)

[long pause] Yes.

Researcher

Would you like to tell me about it?

Nurse

Somebody who had enormous leg ulcers. It was overseas [in a nursing home]. We were putting on dressing every day, we were very fortunate there. She had a quality of life yet again, although she had a lot of pain in these legs, was out and about, but she developed pneumonia and they wanted to let her die because of these leg ulcers that she had had for years. I said, "You can't do that" and so he [the doctor] sat in my office for ages and I said, "You can't do that, please give her antibiotics" and I said, "please give her antibiotics" and he and I marched down to matron. I said, "Who is going to turn round and tell her family that you don't want to treat her?" So reluctantly they gave her antibiotics and she did recover. Her leg ulcers did heal because I was in that home for nine years.

Researcher

So if you hadn't been there, if someone else had been there, she would have died?

Nurse

Yes, she would have.

4.5 (3.6) Age of Patient and Issues Relating

In general terms, the patient's age had some influence on nurses'⁵¹ decision-making process but many of the participants⁵² made the majority of their decisions based on the

⁵⁰ Participant Six

⁵¹ Participants One, Five, Seven.

patient's physical condition, rather than age. Even where the patient had to be admitted to hospital in order to receive medical intervention, age was not a factor in the decision-making.⁵³ Three participants did include "quality of life after medical intervention" as a factor; however, in general, they acknowledged that ultimately it was the patient and/or the family who should make the decision.⁵⁴

Another nurse resorted to pleading with a doctor to send an eighty-five year old lady to a stroke rehabilitation unit, in order to give her a chance to live. On this occasion, the doctor accepted the nurse's decision, complied with her request and the patient survived.⁵⁵

Nurse (Participant Six)

Well, the GP came and I said, "Please can we send her to the stroke rehab unit?" Of course, the person's age was taken into account. I said, "It doesn't matter, age doesn't matter."

Researcher

How old was she?

Nurse

She's eighty-five, well she's eight-five now, she would have been eighty-three at the time. I said, "Age doesn't matter. This lady was down in the greenhouse, planting, arranging flowers, looking at all the plants, on outings, doing all sorts of things. You can't just wipe that away. Give her a chance." I was told, "All right, you're very persuasive we'll do it." And it worked, I mean, O.K. she's not as fantastic as she used to be but she still does a lot of things.

⁵² Participants Two, Three, Six, Ten.

⁵³ Participant Two.

⁵⁴ Participants Two, Three, Six.

One nurse found it very distressing when a doctor insisted that a ninety-seven year old lady should be admitted to hospital for various tests, including an electrocardiogram, blood counts and carbon dioxide levels. She suggested that, due to the patient's frailty, these tests should be undertaken in the home, but the doctor insisted that she be moved to the hospital.⁵⁶

4.5 (3.7) Futile Care

Treatment was sometimes given where nurses considered this futile. Participant Five responded to a relative's request, moved the patient to hospital even though there was little prospect of recovery, simply to assure the relatives. She also stated that 99% of the relatives would not want the patient going through the trauma of being transferred to a hospital for treatment and would opt for them to remain in the care home. She had also experienced two patients receiving PEG tubes when, in her opinion, it was futile on both occasions.⁵⁷

Nurse (Participant Five)

We've had two people with PEG tubes who I really felt, "I don't know what your quality of life is, I don't know why this is being done."

Researcher

Were they conscious?

Nurse

They were conscious, but they really were very unresponsive. They didn't speak back to us. It was really done to prolong life rather than maintain a quality of life, I felt, but we had another lady who had Parkinson's disease who had a PEG tube who was having great difficulty swallowing. She was a younger lady and she had a PEG tube put in and she had 6 months of really great life with it. I think there is a time and place for it.

⁵⁵ Participant Six.

⁵⁶ Participant Five

⁵⁷ PEG - Percutaneous Endoscopic Gastrostomy

Participant eight related a situation where a relative, who was unaccustomed to visiting the patient, telephoned the care home making “outrageous demands” about the patient’s care. In her opinion to give the care requested was futile, since the patient was dying.

Researcher

We’ve talked about being there. Have you ever had demands from the relatives for futile therapy? [Example given of what that means].

Nurse (Participant Eight)

Yes, we have. We’ve had a few cases. Usually one member of the family makes outrageous demands whilst the rest of the relatives are quite happy with the care that is going on; their relative is looked after, they are cared for and comfortable. We had a case when the resident was on subcutaneous fluids and she had a change in her condition, which made the quality of life and prognosis not good. The next of kin had been prepared for this and they made the decision with the doctor to withdraw fluids; but then another relative, someone who had never come to see the resident, rang up in a state and demanded that we start fluids again because a member of the family was on holiday and they wanted the resident to be alive when the person came back from holiday.

4.5 (3.8) Decision-Making and Patients With Dementia

When devising a care plan for a patient with dementia, the nurses planned as if the patient did not have dementia. In participant five’s opinion, there was no difference.⁵⁸ However, participant two acknowledged that relatives might view the person differently, simply because they would be comparing them with a time when they did not have dementia.⁵⁹

Researcher

When somebody has dementia, does that influence your decision-making process when it comes to whether you would come to admit them to hospital or not?

⁵⁸ Participant Five.

⁵⁹ Participant Two.

Nurse (Participant Two)

I don't think it does really because somebody with dementia could be very happy in their own little world. I don't think it does. It may well be for their relative or next of kin because that won't be the person they married or their mum or dad, so it would be different for them, but I don't think it would influence my decision too much.

Participant eleven stated that the same equity was given to those patients with dementia who required resuscitation. However, she acknowledged that the relative's preferred care and treatment, which the nurses always followed, would usually be documented in the patient's care plans.

In general it was more difficult to determine the level of pain in someone with dementia. Participant eleven based her decision by comparing how the patient had been prior to the illness and hoped she was making the right decision, feeling confident that she had, because she always acted in the patient's best interest.

4.5 (3.9) Dependency on Doctors' Decisions

At times, nurses depended on a significant input from the patient's G.P. to support their decisions. On other occasions, the G.P. would seek the opinion of nurses, acknowledging their knowledge on end-of-life issues, as well as their expertise on giving treatment such as subcutaneous fluids and medication.⁶⁰

If there was any disagreement, a compromise between doctor and nurse was usually found. However, occasionally a doctor from "the old school" would expect the nurses to

⁶⁰ Participant One, four, Seven, Eight, Eleven.

carry out his orders⁶¹ and in reality the doctors usually had the final say on matters of treatment or care.⁶² Such was an example where a G.P. refused to respond to a call to attend a patient in the home and the nurse was forced to call an ambulance against her better judgment. This resulted in a very unsatisfactory outcome, for the patient and the nurse.⁶³

Researcher

How do you make the decision or what criteria do you use to decide whether someone should go into hospital – is it knowledge as a nurse, is it your personal values, or is it something else in your experience?

Nurse (Participant Two)

A lot of decisions are taken out of our hands really and made by G.P.s, paramedics, depending on the situation at hand really but I feel a lot of it is actually taken out of our hands and the decisions are made for us. I can think of an incident recently where an elderly gentleman in his nineties was found slumped under his bed – phoned the G.P. – he (the patient) had not much of a quality of life to start with. He had had vascular dementia, not mobile, incontinent, didn't know his family or friends and just sat in his room. He was found slumped over the bed with a very slight pulse, not much of a blood pressure at all. I phoned the G.P. as it was still in hours and the G.P. refused to come out and told us to phone 999, which we did and there was a discussion between the nurse in charge and the paramedics. The nurse in charge thought that he had passed away because there was no pulse, but the paramedics, because they had been called, were adamant that they had to resuscitate him, which they did for ten minutes and then they took him outside and continued for another ten minutes and then they blue lighted him (sent in an ambulance as an emergency) all the way to the hospital, but he was dead on arrival.

Participants five, six and ten had had similar negative experiences with G.P.s where they were left feeling helpless. Participant eight claimed to have more knowledge than doctors regarding the physical care of the patient and “the nursing side” but,

⁶¹ Participant Eight.

⁶² Participant Ten.

⁶³ Participant Two.

acknowledged that doctors were more knowledgeable on the actual “medicine side” [not only medication]. Anything “medical” would be referred to the G.P.

4.5 (3.10) Years Trained and Experience in Nursing (Care) Homes

Although most of the nurses had been qualified for over ten years and during that time had worked consistently with the elderly in care homes, others had embarked on a nursing career later in life.⁶⁴

Participant one stated that her years of experience enabled her to use her own initiative to prioritise care and organise staffing levels, as well as assess the patient and make decisions on medication, nutrition and hydration. She had a career break at one time but considered that caring for her family complemented her nursing experience and contributed to how she made decisions. Participant two, with thirteen years of experience, reflected that, although experience was “something you gain yourself as you are going along,” it was difficult to know whether that was good or bad experience. She made decisions on each individual patient, based on her own personal feelings. Although one nurse had only been qualified for three years, as a mature person she felt that her life experience and her “love of the patients in the home” helped her to make decisions.⁶⁵

⁶⁴ Participants had from 10 to 38 years of nursing experience (mean 19.19 years, SD (standard deviation) 8.92 years based on this sample) and between 3 and 22 years experience of working in care homes (mean 11.95 years, SD 7.00 years based on this sample).

⁶⁵ Participant Eleven.

4.5 (3.11) Decisions Relating to Medication

Participant one stated that it was her past experience that had enabled her to make judgments on the prognosis of a patient who had a stroke, as well as the nursing care and pain-relieving medication. Not only that, but the G.P. trusted her to make those decisions.

Researcher

So would you say, (summarising) you really make your decisions out of experience, past experience, learned experience.

Nurse (Participant One)

I would say it was out of experience, also getting the doctor here as well. The doctor saying to me that, "This lady is very ill and poorly and, are you happy to keep her here?" The doctor saying that, I knew and obviously, I could see by the woman's condition, I knew it was really a very bad stroke and my thoughts at that time were, it is only a matter of time with this lady. Also, the thing is as well, when you work in a place, I think you always rely on feedback as well from your colleagues and what your colleagues think as well. If I was at all unsure about anything, I would always speak to my colleagues and say, "what do you think?" Even things like, this person was actually put onto diamorphine and after it was prescribed, after going to assess the lady, I thought, "No this lady actually doesn't need this." You know, it could have just been gone and administered, the fact that it was prescribed, but I went through and thought, "No, she's settled down again and I don't believe that we should just be giving it for the sake of giving it." I went and spoke to one of my colleagues and discussed it with her and she agreed with me.

Researcher

So why did the doctor prescribe her diamorphine?

Nurse

Because I spoke to the doctor because she (the patient) was very very agitated and she was thrashing about and I was obviously concerned that the woman was agitated because of her cerebral irritation or whether she was in pain. It was also very alarming for her friends, sitting with her twenty-four hours a day and, I spoke to the GP about it and the GP prescribed the diamorphine. However, like I said, after we actually got it, I thought "I don't think she really needs it now."

Researcher

How did the doctor feel when you said that to him? What did he say to you?

Nurse

The doctor was fine, the doctor was happy for me and my colleagues to use our own initiative, our own assessment and, if we thought she needed it, we should just go ahead and give it; however, the doctor was happy to take our word that, if we didn't think she needed it, then that was fine.

However, participant four's experience was quite different. Although the family did not want the patient to be in pain, they would not allow morphine to be given, since they had "some misconception about morphine." As an accountable practitioner, she felt extremely compromised, for had she wished to give morphine to relieve the patient's pain, first, the relatives would have had to be consulted and then, if need be, she would have had to persuade them to accept her decision. Participant six had a similar experience, but would have acceded to the relative's wishes, even if she had disagreed with them.

Researcher

How do you make the decision when you involve them (the relatives) and when you don't?

Nurse (Participant Six)

Well we involve them when they (the patients) go onto analgesia. As it steps up into the controlled drug area, we do inform the relatives mostly what is happening and are they happy with this situation and are they happy with the care that their relative is having?

Researcher

If they disagreed about the medication and dose, what would you do?

Nurse

We would all have to get together with the family, the G.P. and anyone else who was involved. We would have to meet and come to some sort of decision. Ultimately, if the client is able, it is his choice.

Researcher

So the client has the final decision and after that?

Nurse

After that, the relatives.

Researcher

Not you?

Nurse

Rarely. That's an interesting one.

Researcher

Why is that?

Nurse

I won't go against a relative. It's their father, their mother, not mine.

Participant five would modify her language to suggest that the patient required more pain relief, by saying to the family, "things aren't going as well as they were; we don't think we are keeping on top of her pain." Although it was not an automatic decision to increase medication dosage at the end of life, similar to other nurses,⁶⁶ she considered it necessary to gain consent from the family, if an increase in pain or symptom control was necessary.

Participant seven had experienced relatives covertly, asking that the medication dose be increased.

Researcher

Have you ever been asked by the relatives to increase the medication, not for pain control, but with the knowledge that to do so would hasten death?

⁶⁶ Participants Four, Six, Seven.

Nurse (Participant Seven)

They've never actually said, "will you increase the medication, or could you" but what they have said is, "How long is this going to take, could it not happen quicker?" You know, they kind of go along that sort of line. They are not actually directly saying.

Researcher

How do you answer that?

Nurse

I'm very open to them and say to them, "We will not increase the medication unless we feel it is necessary to make them comfortable." Our main aim is that they have a very peaceful, comfortable end to their life. If we felt that the pain was not controlled properly, well yes, we would increase it. If they were getting very restless, then yes we would consider adding something to the medication already given, to make them more comfortable, but there is no way we would increase the medication unless there was a specific reason for it. Just to hasten the end of their life is not one of them.

Where a patient is nearing the end of his life and is unable to take oral medication, a morphine syringe-driver can be used to administer medication. The decision to use a syringe-driver is made in consultation with the G.P. According to participant eight, the patient is assessed by a pain assessment tool, but also her "feelings." However, where the patient was unconscious she would administer morphine via a syringe-driver as a matter of course.

Participant ten was extremely cautious about giving morphine via a syringe-driver. She stated that she would ensure the patient was not in any pain, but was reluctant to give pain relief since the Harold Shipman case.⁶⁷ This had made her more aware of her accountability in giving medications.

⁶⁷ Dr. Harold Frederick Shipman (14 January, 1946 – January 13, 2004) sentenced to 15 consecutive life sentences for murdering fifteen patients, although evidence to suggest he had killed over 200 patients. He committed suicide whilst in prison. [The Shipman Inquiry (Crown Copyright 2001) [Online].]

4.5 (3.12) Decisions Relating to Hydration and Nutrition.

When a patient suffered a stroke, the nurses would make decisions to determine the patient's immediate care as well as his long-term welfare. Based on past experience, participant one did not think it necessary to give such a patient any means of hydration.

Researcher

Nursing somebody who is dying, as this lady was, how long did it take from the time of the stroke until the time that she had died?

Nurse (Participant One)

About six days.

Researcher

Six days. So during that time, did she have anything to drink at all or any kind of nourishment at all?

Nurse

No.

|-----|

Researcher

Do you think (pause) and this is a hypothetical question, if she had gone to hospital and maybe given an intravenous infusion, do you think there would have been any chance of recovery at all?

Nurse

No, I don't really think so. I think through past experience of what I have seen, because there was so little response; I don't think that she would have made any recovery at all.

Participant two had a different experience with stroke patients; she opted to ensure that they were given fluids. First, she discussed how she cared for an elderly lady in her nineties, without any relatives and who was generally deteriorating and coming to the end of her life. Although the patient's appetite was greatly reduced and she had lost a lot

of weight, the nurse decided to give her supplement drinks to try and stop the weight loss. Patients with a stroke, or frail patients, were treated in a similar way.

Researcher

Looking at “physical symptoms” and especially nutrition and hydration, how do you deal with somebody who has had a stroke or is frail, or is dying, how do you nourish and hydrate them, or do you just leave it?

Nurse (Participant Two)

I don’t think you just leave it. If they have a swallowing reflex and are still able to take something, just the best you can really; liquidised meals, fluids, the best you can and just try on a daily basis and adapt to their individual needs.

Researcher

And if they don’t have a swallowing reflex, what happens?

Nurse

The decision is either made to keep them here and give T.L.C. [tender loving care] or to go to hospital for I.V. Fluids

Researcher

And if someone said to you, “Nurse when I am dying, I don’t want you to give me any food or water, nor treat me, or anything like that,” how would you feel about that?

Nurse

I think I would feel very compromised. You don’t know if that was a rational moment really that they were saying these things to you. It would be very difficult.

Where a patient with a recent stroke could communicate with nurses, their preference for treatment in the care home or in hospital would determine whether they received subcutaneous fluids (in the home) or intravenous fluids (in hospital).⁶⁸

⁶⁸ Participant Four, Five.

Researcher

What happens if someone has a stroke and there is a decision not to put in a PEG tube and there is a decision to “let them go”, do you give them any fluids?

Nurse (Participant Five)

We have given subcutaneous fluids.

Researcher

Is it effective, does it work?

Nurse

It seems to, because one lady who had previous CVAs (cerebral vascular accidents) [pause] and she had another turn and she had gone deeply unconscious for a while [pause] and she couldn't swallow anything and the family didn't want her to go to hospital, but they wanted something done, so the G.P. suggested, since she wasn't able to swallow anything herself, subcutaneous fluids for three days and then to make a decision whether we would have to help her get on or what's to be done at the end of that. Then she rallied, so there was obviously enough hydration for her to get going again. We have used it in end stage with a couple of residents, but again there are two schools of thought on whether hydrating people actually make them any more comfortable.

Researcher

What do you think?

Nurse

As long as you are keeping their mouth moist, it's hard to tell because you don't know what sort of headache they have, although they don't seem to be restless with you. I think if they had a headache or pain that they would be restless, but I haven't seen anybody being restless who hasn't been controlled with the medication that has been given.

If a patient were unconscious as the result of a stroke or had dementia participant five would discuss the situation with the family and then make a decision on the best course

⁶⁹ Participant Five.

of action and whether to give nutrition and hydration. Some care homes did not provide for the administration of intravenous fluids and others did not provide the means for subcutaneous hydration.

Participant Seven

.....what you tend to do is talk to the relatives, as the days go past, as their (the patient's) condition deteriorates and they are not able to drink and of course their swallow reflexes are gone and [talking to the relatives] we will not be putting a drip up, but if you have concerns and you want your relative to be hydrated, you do realise that it needs to be discussed with the G.P. and they (the patient) will have to go to a major hospital.

4.5 Summary

Nurses make decisions based on knowledge, a “knowing”, intuition, experience and personal belief systems. They perceive their role as enabling the patient and caring for the relatives. Relatives are usually included in the decision-making, but doctors make the final decision. Age and mental infirmity does not influence the decision-making process negatively. There is no clear consensus for assessing the provision of pain-relieving medication and artificial nutrition and hydration.

4.6. (4) Emotions

4.6 (4.1) Relatives' Emotions

According to participant two, relatives often experienced profound emotional turmoil at the end of the patient's life and it was important to consider their needs when evaluating the patient's needs.⁷⁰ Emotional distress would often manifest itself in the relative expressing a wish, that the patient would “just slip away,” especially where they had

⁷⁰ Participant Two.

been maintaining a vigil with the patient for several days.⁷¹ At times, the relatives gave vent to their emotions by criticising the nursing care and one nurse perceived this as being a sign of mental and physical exhaustion.⁷²

Participant eight had experience of relatives, who were not in the habit of visiting the patient, over-reacting to a death and described how one relative telephoned the home, came in to see the patient and started “wailing and crying.” However, participant ten reflected that some relatives were more interested in the material gain than the death of the patient:

Researcher

These people [the patients] didn’t know they were going to die, except for the one [patient] who refused to eat and drink. Yet, they were dying. So what happened, did you send anyone in to sit with them?

Nurse (Participant Ten)

No. I sent someone in with one of them. I do try and do that if the relatives aren’t present; but the one that the carer saw was dying, I did ask her to stay with her [the patient] and I think I was maybe seeing to one of the other ones and I said, “I will be up shortly” sort of thing, but I had seen her [the patient] not long before. There was no sign of shut down or anything like that, but I felt bad about that because I hadn’t got the family here. To be honest, I am not sure if they would have really worried, they were more interested in getting her wedding ring off. I was sickened by that but there was no other way of dealing with it. They were concerned with more material things than whether she had been in pain or anything like that.

Researcher

Was she alone, or whatever?

Nurse

Yes, I think I managed to get that out, that there was [now] somebody with her, but it was, “Will her wedding ring come off?”

⁷¹ Participant One.

⁷² Participant Five.

The key to reassuring the relatives during this difficult time was to enable them to feel comfortable with the staff and secure in the knowledge that their relative was receiving all nursing care. In addition, encouraging them to phone or visit at any time of the day or night, offered them the opportunity to come to terms with the patient dying.⁷³

4.6 (4.2) Fear

Participant eleven observed that some patients appeared to experience 'fear' during the dying process, especially at night and, although she had not experienced anyone being frightened whilst dying, she thought it possible. She described a patient, who had stated that she was ready to die and join her husband, but was frightened to die alone.

According to participant seven, where the patient expressed particular fears, the nurses would explain to the patient, in practical terms, what would happen once he or she had died. She re-iterated that one patient had asked how it would feel to die, but she had to tell her directly that she did not know, but that she would ensure someone would be with her when she died.

4.6 (4.3) Guilt

Participant two had experienced relatives querying the nurse how much longer the patient had to live and at times this was so that they could make plans to go on holiday. She felt guilty if she made a wrong guess and the patient died without the relatives being present. According to her, at times relatives made allegations of neglect that the patient had been left to die without anyone present. Although this would demoralise the

⁷³ Participant Eleven.

staff, it was accepted as an expression of the relative's guilt, at not spending much time with the patient whilst he was dying or being present when he died.

Participant six related how on occasion, the relatives would become more "distant" from the staff or complain unnecessarily that the patient required pain relief, a sign that they may be experiencing feelings of guilt that someone else was looking after their loved one, especially where the patient had involved the staff in confidences about their final wishes, but had not shared the information with the relatives.

Participant four described how there are cases where relatives have sat for many nights with the dying person and then leave the home for half an hour, only to find on their return that the patient had died. She said it was really difficult for relatives and hard to accept and left them with feelings of guilt.

Three participants thought that some relatives felt guilty about putting their relative into care and required a great deal of reassurance that they were content and cared for in the home.⁷⁴

4.6 (4.4) Hope

Although the participants believed that it was important for patients and their relatives to have hope, they also felt that it should be realistic and not based on false information. Participant five stated that she tried to prepare the relative for the patient's impending death. She did not diminish hope but would inform the relative that the patient was

⁷⁴ Participants Six, Eight, Eleven.

“very poorly,” that they did not know which way the patient would go, but that it was possible that he “could rally through for a while.”

Participant six considered that the only hope she could give a dying patient, is that she could be there for him or her. In her opinion, it was unreasonable to say to somebody “You’ll be fine, everything is going to be fine, when it is not going to be fine.” She thought that, since patients were already in their twilight years it would be very hard to give hope that they might recover from their illness.

One nurse informed the relatives that in giving the patient antibiotics there was a possibility that she might respond to them; although the patient died, in her opinion, there was always room for hope:

Nurse (Participant Eleven)

..... I related what the doctor said to them that we were giving their mum antibiotics and that she may respond to them, but then again, that might not be the case; but then they ask you, “Well, when?” That’s always difficult because that’s a hard one for nurses, because you just don’t know.

Researcher

What did you say?

Nurse

Well, I just said, well let’s see how mum gets along. We have given her two doses of antibiotics, let’s see how she is tomorrow, but I wasn’t to know, because she died before the next day.

However, participant ten stated that she did not give hope to the dying. She hoped that they might be pain free and that she could give them hope in that respect. Hope, as in survival, she considered false hope.

4.6 (4.5) Grief

As the patient arrived at the end of his life, the staff in the care homes experienced a sense of loss and grief. Participant one made a point of ensuring that the staff had an opportunity to grieve by inviting them to say goodbye to the dying patient, although, in her opinion, the feelings of the staff were not always considered.

Researcher

What you have given me is your feelings about how you look after people and how you make your decisions. Is there anything else you want to tell me at all? Just have a look through the Interview Guide and see if there is anything that triggers your memory and that you would want to tell me.

Nurse (Participant One)

I should mention as well about grief.....A really important point is our staff as well, because a lot of times staff aren't considered. I remember like one lady that we had dying, I can remember saying to the staff, "do you want to go and say bye-bye, I think she is going to die soon." Quite a lot of staff would say, "Yes, is that O.K.?" They went in and they held her hand and said a wee thing or gave her a kiss on the head or something. That was like part of letting them know that the lady was going to die and that part of them accepting it and giving them the chance to go and say bye bye.

[Continues]

..... they need to be given the opportunity to grieve and if that means, well go and have an early lunch or go and have a fag (cigarette) and a cup of coffee, I think we have to consider that as well. I think at one time as a carer whatever, we were just expected to put on a brave face and get on with it.

Grief can manifest itself in many ways, for patient, relative and care staff. Participant seven reflected on one incident in the care home where the relative could not accept that her mother's life had ended. When the nurse arrived to start her duty shift that day, much to her amazement, the relative rushed past her and continued on straight out of the care home. Later that day, the relative came back, hugged the nurse and related that she had to leave, just to "get a breath of fresh air." She also described a second incident, after the patient had died, where relatives complained about his care. This left the nurses feeling distraught and questioning their practice, but as they reflected on the incident, they realised that the complaint was a reaction to the patient's death.⁷⁵

Where nurses had built a close relationship with the patient, their loss was akin to losing a good friend and the grief reaction was similar.⁷⁶ Participant three became angry with the carers who fussed over a dying patient and expressing outward signs of grief by going to the patient's funeral. In her opinion, although probably a coping mechanism, their grief was false and hypocritical, since they had not spent much time with the patient when he was well.

4.6 (4.6) Peace

Participant four stated that the most important thing for both patient and relatives was a peaceful death. In her experience, most patients, although not all, were more at peace if some-one was present at the time of dying. She also felt that the nurse's role was to help the person find peace before they died.

⁷⁵ Participant Seven.

⁷⁶ Participant Eight.

Participant five noted that, by being there and letting the patient know they were not alone, gave them a sense of peace, whilst participant seven observed that it was usually when the patient was coming to the end and was unaware of the “day-to-day goings on,” that they finally found peace.

4.6 (4.7) Nurses’ Emotions

Although the nurses retained their professionalism throughout the patient’s dying process, many of them experienced intense emotional feelings. Participant one described how, on one occasion, she witnessed a patient suddenly screw up his face as if he were in pain, “almost as if he had had a heart attack” and then take a deep breath and die. She was extremely relieved that his wife had happened to turn away at that moment and had not witnessed this last action. The patient and his wife had been together for fifty or sixty years. She felt very upset that the elderly wife was now on her own in the world. She related how when she retreated to the staff room for a cup of coffee, she just burst into tears at the thought of the wife being alone in the world. [Whilst discussing this incident the participant became visibly upset and the researcher moved away from the story].

Since patients normally resided in the homes for lengthy periods (up to ten years), the nurses built strong relationships with them, as if they were friends.⁷⁷ Participant three described how sometimes they laughed and cried with the patients and sometimes they felt sad, especially for those patients with dementia. Participant eleven experienced

⁷⁷ Participant Two.

great joy from working with the elderly but found it difficult to break bad news to a relative.⁷⁸

When participant ten persuaded an elderly man to overcome his reluctance and be admitted to hospital, she described her feelings as “awful” when he died. Both she and the patient had expected him to return to the home after treatment. Other emotions were ones of quiet reflection and tenderness. When an elderly lady with dementia died in the care home, participant five quietly said to the dead patient, “Oh, I am going to miss you.”

At times, caring for dying patients could be an emotional experience for the nurses, but they retained a professionalism, which allowed them to distance from the emotion and make clear decisions with regard to the patient’s care.⁷⁹

Researcher

Do you ever get angry with the relatives, staff, patients, doctor?

Nurse (Participant Eight)

I am just trying to remember when I last was angry at anything at all. No I tend to detach myself from the residents, relatives, doctors etc. I don’t get angry even if I feel it inside; I try not to let that show. I think that is quite unprofessional and it can be quite unsettling for the residents and for the relatives. It is obviously an upsetting time for the residents who are dying. It is not good for them to see that their relatives are upset.

Researcher

So you very much see yourself as the nurse who is in control?

Nurse

Not in control, but maybe acting as a sort of mediator between all these parties. I wouldn’t like to think that I was controlling anybody. Not control.

⁷⁸ Participant Eleven.

⁷⁹ Participants Three, Eight.

4.6 (4.8) Nurses' Feelings and Job Satisfaction

In spite of the emotional difficulties, the nurses expressed their commitment to caring for the elderly, including those elderly patients with dementia who were not always aware of the nurses' input. Participant nine affectionately remembered one patient with dementia from some time in the past.

Nurse (Participant Nine)

Well, they are a different person to what they once were, but they are still very much individuals. I find it most rewarding, especially when you get a reaction from them when you least expect it. I remember one lady who could not even remember my name. At that time, my hair was longer than it is now. I went on holiday for two weeks and when I came back, she said, "You've had your hair cut." I was really pleased to see that she recognised and remembered me. Things like that make it worthwhile. She couldn't remember anything else about me, but she knew that I had had my hair cut.

In addition to being appreciated by the patients, participant five enjoyed receiving letters from the relatives thanking the nurses for their care and being recognised for having done their best. Participant two expressed how much pleasure it was to work with the elderly.

Researcher

What is it that drives you and makes you want to look after the elderly?

Nurse (Participant Two)

I just find it so rewarding. They don't ask for anything. They don't take from you, they give so much back. They have so much to share with you, so many life experiences. They are just grateful for anything that you do for them. I love my job, yes I do, I love looking after the elderly. That was the first ward that I did in my student nurse training and it has always been my favourite.

4.6 Summary

Nurses, patients and relatives experienced the same emotions, which manifested in different forms. However, nurses perceived their role as supporting the patient and relative through their emotional difficulties. The nurses were satisfied with their role and considered it more than just a paid job.

4.7 (5) Duty To A patient

4.7 (5.1) Duty

The nurses' sense of duty was derived from a realisation and understanding of the contribution the elderly had made to society. Participant nine felt passionately about the contribution that the elderly had made and how society appeared to be neglecting the elderly. They saw it as their duty as professionals to provide that care for the elderly and to assist the doctor in caring for the patient.⁸⁰

Researcher

Do we have a duty to care for these patients?

Nurse (Participant Nine)

They have worked hard all their days. They maybe did not have the same opportunities as we have. This society leaves their old people – they are left alone in their houses. This society has changed their attitudes. The government does not put enough money into our area [caring for the elderly]. What we need is education, more funding, more places to look after them [the old people] and educating the people. It is so stressful for the relatives. Their life comes to an end when they have to look after their loved one twenty-four hours per day. There is very little respite care available. If other people helped and there were more places for the elderly, it would help the attitude of society.

⁸⁰ Participants Five, Nine.

4.7 (5.2) Accountability

Since nurses are accountable to a professional body, as professional nurses, they were conscious of their practice and any legal implications, especially where they had to administer medication.⁸¹ However, participant eleven stated that she was reluctant to contest a doctor's decision on medication dosage, since she regarded the prescription of medication as the domain of the doctor.⁸²

Researcher

Have you ever disagreed with the doctor at all?

Nurse (Participant Eleven)

No. I can't say I have. No, I have never disagreed. I have never come up against a barrier when somebody is dying. They have always been [pause] they always respect what the nurses are saying. If we are saying, well we think somebody needs further pain control, then they are very happy to [pause] well in the end it is the doctor's decision, it is not our decision, is it?.....

..... Well I am responsible as well for knowing that that person is in pain. It is up to me to be aware of that, isn't it? It is up to me to tell him that this person is in pain. We are accountable for our own practice.

Researcher

What if you felt that the doctor was giving too much Oramorph? If you felt, well he [the patient] doesn't need all that, what would you do?

Nurse

Well, there is nothing I could do. I am not allowed to alter the dose without the doctor's consent. So all I could do is go back to the doctor and say, "I feel the patient is being given too much Oramorph" and hopefully he would listen to what I was saying. There is no way that I could alter that myself because I am not allowed to do that. I would have to [pause] again it is back to the doctor, isn't it really? You can only tell the doctor what you perceive.

⁸¹ Nursing and Midwifery Council for Nurses and Midwives. "Standards for Medicines Management" [Online].

⁸² Participant Eleven.

Participant one stated that, if she had any query with regard to the medication dose, she would first discuss it with her colleagues and then gain an opinion from another doctor and on his say would give the dose originally prescribed by the first doctor.

If the patient required any treatment or care intervention, the nurses would discuss the options with the family, but would not necessarily carry out the family's preferred option.⁸³ Since nurses were aware of their accountability and the potential for litigation, if any of the relative's requests were inappropriate, they would document it and then pass it back to the G.P.⁸⁴ As one participant described, "Put it in his hands; pass the buck if you like."⁸⁵

However, participant eight stated that she would ask to be transferred from the care home if she disagreed with the prescribed care or treatment.

Researcher

You are an accountable nurse. If you disagreed with the care would you continue to work with the doctors or relatives?

Nurse (Participant Eight)

No, I would ask to be moved. If it were detrimental to the patient and not right, I would definitely ask to be moved. I would go to the manager and then see what happens.

Researcher

Would you take it further?

Nurse

I would have to determine that at the time. As someone who is accountable, I would have to be able to justify what I am doing in law.

⁸³ Participants Two, Four.

⁸⁴ Participant Six, Seven.

⁸⁵ Participant Six.

4.7 (5.3) Trust

The experience of each nurse varied but they considered important to build trusting relationships between themselves, the patients, the doctors and relatives. Participant one had a good trusting relationship with the doctors who were inclined to “take her word” for any decisions that she made and trusted her to make the right decisions, a situation similar to the experiences of participants four and six.

However, at times participant two, felt intimidated by doctors and where key decisions were made, such as whether or not to give intravenous fluids or admit the patient to hospital, she could only “hope” for a joint decision and “hope” that she would have some sort of input.

Participant eleven described trust within the relationship in the following way:

Researcher

How do you see trust in the relationship between the patient, the family, the nurse and the doctor?

Nurse (Participant Eleven)

Oh there has got to be trust between all of them, hasn't there? I think so, because the relatives trust us as nurses to look after them [the patients] and we trust the doctors to keep us right as to what medication they are having and the patient themselves trust us all. The patients, if they are aware, trust us to look after them until they die.....[without that they]would feel insecure and would be frightened to die.

Participants seven and eight stated that if the patients did not feel comfortable with the staff and trust that the staff would always be truthful, care could not be delivered

appropriately. Several participants felt that, if relatives trusted the staff, they would know that the best possible care was being delivered to the patient.⁸⁶

4.7 (5.4) Advocacy

In providing the best care, the nurses acted as advocates for the patients. On one occasion where a patient had decided that he would not eat, participant one stated that she “had to interfere” and stop the process. She did not have the ability to stand back and do nothing and by referring him for admission to hospital, ensured that optimum nutrition and hydration be given.

Participants five and six regarded, “acting as an advocate,” as one of the most important qualities of a nurse. Participant ten stated that she would always try to intervene on behalf of the patient, but, although she saw herself as the patient’s advocate, she conceded that at times it did not always work out as she desired.

4.7 (5.5) Best Interests

Although the nurses considered that they had a duty to do the very best for every patient, the term “best interest” was not uniform and meant different things to different nurses. Participant eleven used her knowledge, experience and instinct to determine what was in the patient’s best interests. Participant two found it difficult to know what was in the patient’s best interests, describing that it was “more what she felt was best for them,” and participant three felt she could only “be there and then judge on an individual case.”

⁸⁶ Participants Four, Seven, Nine, Eleven.

Participant six explained what she thought the term “best interest” meant:

“Let’s put on this bandage because it is in your best interest.” I think people are given a choice here, certainly we do say to them, “You had better take this antibiotic because it is in your best interest because it is going to make you feel better. It is going to improve things for you if you do such and such.” I certainly wouldn’t force anybody that didn’t want it. I just said to somebody yesterday, she’s got a nasty toe, and she said, “What is that awful stuff?” “It’s an antibiotic.” “And what is it going to do for me?” I used that phrase, “it’s in your best interest to try and clear that toe so that you can get about again.”

Participant four recognised that relatives could have an ulterior motive, such as hastening death to acquire a monetary inheritance and, if this was suspected to be the case, she always ensured that the doctors were involved in the decision-making process.

4.7 (5.6) Conscience

Participant three considered conscience to be part of the decision-making process.

Researcher

Do you think that a person’s conscience is part of the decision-making process?

Nurse (Participant Three)

Yes, I suppose it is because you must treat everybody fairly. I mean you wouldn’t force-feed a Muslim, pork, that would be bad, that would be unjust. You have to use your conscience, to decide what is good and fair for the resident, what is best for the resident, so in that way your conscience plays a part in making the decision.

Participant nine reflected that she thought her conscience was formed in the early years by her parents who were “not really religious but good living people” and developed over the years. She believed her conscience did inform and contribute to how she worked as a nurse. Every evening, as she drove home from work, she would go over in her mind and think to herself, “Now, have I done the right thing by that person today,

did I do that right?” Having been a witness at a U.K.C.C. hearing, she was inclined to be sure that everything she did was right, since she was aware of the legal accountability for her practice.⁸⁷

4.7 Summary

The participants felt that they had a duty to care for their patients and undertake what was in their best interests. They considered it important to act as advocates for the patients, build trusting relationships, whilst being accountable for their practice.

4.8 (6) Patients’ Rights

4.8 (6.1) Autonomy

The participants did not always use the word “autonomy.” Instead, they referred to “the patient’s decision” and “the patient being in control of his pain relief medication,”⁸⁸ “the patient being very involved in their care plans” and “the patient making his wishes known,”⁸⁹ and the nurse “being unable to ask the patient with dementia.”⁹⁰ Participant ten reflected on one situation in the home where relatives were determined not to inform the patient that he had cancer. The staff were unhappy about the situation, but co-operated, unwillingly, with the relatives.

Nurse (Participant Ten)

I have looked after a few people in this situation. It’s quite difficult from our point of view because the carers will have to know, they’ve got access to the notes, they have to be aware that nothing is said in front of the relatives and things like that and it’s again, sort of like euthanasia because it is somebody dealing with your life. You might not be happy finding out that you have cancer, but

⁸⁷ United Kingdom Council for Nursing and Midwifery, replaced by the Nursing and Midwifery Council (NMC) in June 2002.

⁸⁸ Participant Seven.

⁸⁹ Participant Four.

⁹⁰ Participant Eight.

it could be the making of a person. They could totally stand up and fight it; but your time's up when your time's up, isn't it?

4.8 (6.2) Consent

Participant five related that it was not always possible to gain consent from the patient and nurses were obliged to gain consent from relatives, the G.P. or any other legal advocate.

According to participant seven, gaining consent from the patient could be problematic where the patient was adamant that he did not want treatment. She remembered an incident where a patient was in pain, but refused to consent to an increase dose of medication because he did not wish to be “drowsy.” In this particular situation, the only way that she could gain consent from the patient was to inform him of his options and discuss a course of action, leading him to consent to an increased medication dosage. In her experience, if a patient's pain increased at the end of life, “he would become so worn down” that he would usually give consent to increasing the medication dosage.

4.8 (6.3) Dignity

Participant two felt that “dignity” was imperative to ensure that the dying process was peaceful and associated with the patient's dignity were privacy,⁹¹ as well as, reverence and respect.⁹² To die with dignity meant to die pain free surrounded by family, relatives and the staff in the care home.⁹³ Participant four remembered a patient who wanted to die alone. At the time, she felt he lacked privacy because the relatives surrounded his bedside anxiously. One day, when the relatives were not in the care home, the patient

⁹¹ Participants Four, Eight, Nine.

⁹² Participant Eleven.

died. Participant five had similar experiences with several patients and their relatives. She, too, thought the patients just wanted to die in privacy.

Participant four observed that the most difficult thing for any patient was loss of dignity through an awareness of being incontinent.⁹⁴ Patients disliked “having to be cleaned up,” as they found this an undignified process.⁹⁵ Participant four thought that it was important that when someone was dying, he should be treated as the person he was in the past, “not just this dying man.” It was also important that the patient should not be in pain but was comfortable and well cared for in every aspect. According to participant six, “Dying with dignity does not mean that you have to take someone’s life.” In her opinion, “we haven’t got the right to take someone’s life.”

Participant five cared for those patients who were unconscious as if they were conscious. She would talk to them as if they had the ability to understand, explaining what she was doing and continued to do so after the patients had died. In her opinion, this was how to treat a dying and dead patient with dignity.

4.8 (6.4) Value of The Person

Participant six ensured the dignity and respect of each patient when making decisions related to their care, by treating each as an individual; the value of the person was not undermined by age. Participants nine and eleven considered a life valuable because the person was alive, a living being, even after the awareness was gone or where the patient had dementia. Participant three had strong views on the value of a patient:

⁹³ Participant Three.

⁹⁴ Participant Four.

Researcher

Some bioethicists say that a person is not a person unless he is able to reason.....to have the ability and knowledge to understand things and make decisions.

Nurse (Participant Three)

I don't agree with that. We all have free will and no two people are alike, but, if someone has dementia and is not able to reason, they are still human. They did have a normal life beforehand, even if they cannot reason now, so they are still a person and we should treat them as a person, no matter what the person's life has been or whether we agree with that life or not. Being a person has nothing to do with being able to reason. We must treat every human being as an individual, no matter what they are at that moment. They are where they are. It doesn't mean to say that we as nurses are saints or anything, we laugh or cry at some of the situations and sometimes we are frustrated. Our emotions are there, but we must treat everyone as an individual person, no matter what we feel.

Participant seven noticed that some patients felt that they were a burden to the staff and sought reassurances from the nurses that they were not. Participant four explained that every patient was given the opportunity to recover from illness, but, if the natural end to the patient's life appeared to be imminent, he was then allowed to die in peace.⁹⁶

4.8 (6.5) Quality of Life

Quality of life meant that the patients, including those with dementia or wheelchair bound, were able to enjoy the life they had, by working the greenhouse, planting and arranging flowers and going on outings.⁹⁷ However, participant ten did not savour the prospect of becoming dependent on anyone to clean or feed her, stating that this would not be a quality of life. Participant four believed, that if a patient was not aware or was

⁹⁵ Participant Six.

⁹⁶ Participant Four.

⁹⁷ Participants Two, Six, Eight.

unconscious, he did not have a quality of life. She qualified her statement by saying that this did not apply to those patients with a disability or necessarily to those with dementia, since some people with dementia are extremely happy whilst others are not. Participant seven did not understand the benefit of hydrating a patient to extend his life further by two weeks. In her opinion, lying in a bed, unable to do anything, was no quality of life for the patient.

4.8 Summary

The value of the patient's life and his dignity is not based on his dependent status. He has a right to make autonomous decisions and consent is sought for all care and treatments. Quality of life is dependent on the patient's ability to communicate in some way.

4.9 (7) Difficulties

4.9 (7.1) Conflict

In the course of caring for their patients, the nurses often faced situations of conflict where, in their opinion, the outcome had the potential of harming the patient. Often the conflict involved disagreements between the doctor and nurse,⁹⁸ sometimes between the patient and nurse,⁹⁹ at times between the nurse and relatives¹⁰⁰ and on occasions between the doctor and relatives.¹⁰¹

⁹⁸ Participants Seven, Eight.

⁹⁹ Participant Seven.

¹⁰⁰ Participants Eight, Ten.

¹⁰¹ Participant Eight.

Although participant seven normally had a good relationship with the doctors she experienced conflict when one doctor refused to recognise that an elderly eighty year old man required pain-relieving medication via a syringe-driver. Only when confronted with the reality that, without medication, the patient would suffer and his wife would be extremely distressed, did the doctor adhere to her request.

Where there was conflict between the patient and the nurse, it was usually due to disagreement on medicine dosage. Participant seven stated that it took a great deal of persuasion to convince a patient that she required an increase in medication to control the pain. The patient disagreed with the proposed dose and refused to allow any increase in strength, since it had the potential of “doping her up” resulting in her losing control. Without the increased dose in medication, the participant could not control the patient’s pain.

On occasions, where relatives and nurses disagreed on the right course of action for the patient, nurses would make decisions without the involvement of the relatives.¹⁰²

Occasionally, a doctor may cause conflict between staff, relatives and himself. On one occasion, when participant eight called out a doctor from the surgery, she was presented with someone inexperienced who had no knowledge of the patient. Against the advice of the nursing staff and wishes of the relatives, he admitted the patient to hospital. This upset both staff and relatives.

4.9 (7.2) Nurses' Feelings of Inferiority To A Doctor

Although participants two and four recognised that their intimate knowledge of the patient was often superior to that of the doctor, they felt intimidated by or inferior to the doctor. Participant nine stated that when she talked to a patient, she felt much more confident if the doctor was not present.

Researcher

Do you feel like that (the same as the carer's feeling) if the doctor is there?

Nurse (Participant Nine)

Yes, I am more confident if the doctor is not there. I don't know, the doctors are all very nice, but I am always scared I might say something that is not quite right. Things like for example, if I go into a room and say to the patient, "Hello Jim" [fictional name] for example and then the doctor comes in and says, "Hello, Mr. Brown" [fictional name], then I feel as if I should have probably said, "Hello, Mr. Brown".

Another participant stated that where a doctor decided to withdraw medication such as antibiotics from a dying person, even if she disagreed with the doctor, in her opinion, he had the final say.¹⁰³

Researcher

If you disagreed with the doctor, what would you do?

Nurse (Participant Two)

I would voice my opinion. I would try and fight my corner and disagree but you feel very much as if the doctor is over and above your head and they have the final say, but you do try and voice your opinion and put your point across.

¹⁰² Participant Eight.

¹⁰³ Participant Two.

She found it hard to explain why she thought the doctor was “over and above” her head. When the researcher asked, “Do you think they have more knowledge than you do?” she replied:

Nurse (Participant Two)

I don’t really think so, not when it comes to the residents. We’re looking after them for eight hours a day, five days a week. I don’t think so, no, not really.

Researcher

What do you think about their knowledge of nursing care?

Nurse

Non-existent. In that respect, I would say that we as nurses have a better knowledge than them, but you just always feel that they are the superior ones.

4.9 (7.3) Coping Mechanisms

Both nurses and relatives developed strategies to cope with the patient’s dying and nurses felt that relatives would cope better, if they had some idea of when the patient would die.¹⁰⁴ Participant eight coped by developing a sense of humour, which was perceived as benefiting both patient and nurse.

4.9 Summary

Nurses experienced emotional difficulties and complex decision-making at the end of the patient’s life, especially if there was conflict between, nurses, doctors, relatives or the patients. Nurses felt inferior to doctors and this inhibited their actions. Nurses and relatives developed strategies to cope with the patient’s death.

¹⁰⁴ Participants Seven, Ten.

4.10 (8) Support

4.10 (8.1) Nursing Care

Nurses cared for the patients at the end of their lives in many ways, recognising that nursing care was completely distinct from medical care. They talked to the patient to alleviate loneliness;¹⁰⁵ they touched the patient through “cuddles;”¹⁰⁶ gave aromatherapy;¹⁰⁷ gave what they termed as “tender loving care”¹⁰⁸ and they cared for the relatives and friends by providing emotional support and practical help. Participant one’s description of nursing care reflected the many aspects of care that the nurses undertook:

Researcher

As nurses we know that there are various degrees of strokes; was she able to take anything to eat or drink?

Nurse (Participant One)

No, she was un-rousable. She was lying in her bed and she wasn’t able to eat anything. We were having to do everything for her.

Researcher

So tell me what you did for her?

Nurse (Participant One)

We carried out all her personal care, which was washing, changing her, her toiletry, her toilet needs, her skin care, pressure area relief, mouth care, eye care. Her pressure area care, well, we were doing turns. Part of her care was looking after her friends who were in all the time. So we were making sure that they were being fed, that we were spending time speaking to them, giving them the opportunity to express how they felt, so quite a bit of the time was also spent looking after the friends as well, which I think is a very very important part as well.

¹⁰⁵ Participants Two, Six, Eight, Eleven.

¹⁰⁶ Participant Seven.

¹⁰⁷ Participant Six.

¹⁰⁸ Participant Two.

When participant ten was asked if she cared because she was being paid for doing so, she responded quickly:

“Oh no, no, no!”

Researcher

So there has to be another reason then?

Nurse (Participant Ten)

I don't know. In my mind things should be done right. Care; well I don't know how to say it. Not because I get paid, because there are other things that pay far more. A vocation?

4.10 (8.2) Qualities of A Nurse

The nurses identified several qualities that a nurse should have when caring for a patient at the end of his life and these were compassion;¹⁰⁹ understanding, especially of staff and relatives;¹¹⁰ trust;¹¹¹ patience;¹¹² empathy;¹¹³ genuine caring as well as a sense of humour;¹¹⁴ time for the patient, “just sitting with them.”¹¹⁵

Participant nine felt that the ability to communicate was one of the most important qualities that a nurse should have. She said that, the tone of voice, the content of the speech and the manner in which the nurse handled the patient was essential to avoid any distress to the relatives. In her opinion, communication was the most important quality of all.

¹⁰⁹ Participants Four, Six, Seven, Nine, Ten.

¹¹⁰ Participants Four, Six, Seven.

¹¹¹ Participant Six.

¹¹² Participants Seven, Ten.

¹¹³ Participants Eight, Ten.

¹¹⁴ Participant Eight.

¹¹⁵ Participant Seven.

4.10 (8.3) Community Response

Where a patient was dying, the care assistants in one home organised a rota to sit with the dying person and came into the home, in their own time, to participate in that rota.¹¹⁶

The patient and the relatives were never alone and the nurses shared the intimate journey with both relatives and patient at the end of his life.¹¹⁷

4.10 (8.4) Fellow Feeling

The participants considered it important that the patient was aware of the presence of human beings as he lay dying. Participant one described her experience of sitting with the patient, as “feeling something for that patient.” Part of that care was providing comfort to the patient and in her own words, she “felt better” knowing that she was doing something for that person.

Participant two felt it was important to spend the final hours with the patient sharing past memories. In her opinion, this was necessary to give support to the patient and enabled him to die in peace. Often just “being there” for him, sitting quietly with the family and understanding their emotions, enabling them to come to terms with the death of a patient, brought comfort to relatives and staff.¹¹⁸

4.10 Summary

At the end of the patient’s life, the community, that of individual nurses and other staff in the care home, brought comfort and solace to the patient and his family.

¹¹⁶ Participant Four.

¹¹⁷ Participants Four and Eight.

¹¹⁸ Participant Seven.

4.11 Conclusion

Several questions have emerged from the nurses' experiences, illuminating some moral issues relating to end-of-life decision-making. In chapter five, the findings will be discussed in relation to literature in the field of nursing research related to care of the dying. This will be further examined in chapter seven in relation to the discussion on the moral philosophical and theological literature in chapter six.

CHAPTER FIVE
DISCUSSION OF FINDINGS
IN RELATION TO NURSING LITERATURE

5.1 Introduction

This chapter discusses the findings of the empirical research reported in chapter four and their significance in relation to published debates and wider literature in the field of nursing research on care of the dying. In order to meet the aim of the study, these will be further discussed in chapter seven in the light of Christian moral principles.

5.2 A Dignified Natural Death

5.2.1 The Role of Mental Suffering

The general view of the participants is that a good death is one where the patient dies a dignified, natural death, quietly, peacefully, pain-free and surrounded by relatives and staff, allowing nurses time to plan the dying process and cope with the relatives' needs. The participants considered that alleviation of mental and physical distress was essential to the transition from dying to death, but often challenging for them as they found that many patients experienced a sense of knowing when they were going to die, even those with dementia.¹ The findings, similar to those in Costello and Watson's studies of nurses in the UK, and Pleschberger's study of nursing home residents in Austria, emphasises the requirement for skilled management and support to ensure that the

¹ Participant Three, Four Five, Six, Nine, Ten, Eleven.

patient's dying process leads to a "good death."² The participants noticed that many patients appeared to be more afraid of being left alone at night, often questioning whether there was an afterlife and, as well as facilitating a minister of religion when requested, some found that their own belief systems helped those patients who did not have any belief system.³ The intimate fellowship of "being there" for the dying patient brought comfort to them as the participants reached out and touched, cradled, talked, reassured and made the patient feel safe.⁴ "Being present" is a predominant theme in spiritual care and the emotional routine of nursing where the nurse sits with the patient, making that link and "taking their hand" enhances nurse-patient contact.⁵ The participants also considered that the community response and the caring and nurturing ethos of the care home was a distinctive characteristic that enhanced the care of those patients suffering from fear of dying and loneliness.⁶ This supports both Costello's research in UK hospitals and Kayser-Jones' research in USA nursing homes that inadequate staffing can disrupt that community response and impact on nurses' time to listen and show concern and compassion.⁷

² Costello, J., "Dying Well: Nurses' Experiences of 'Good and Bad' Deaths in Hospital." Issues and Innovations in Nursing Practice (2005) November, 594-601 at 597-598; Pleschberger, S. "Dignity and The Challenge of Dying in Nursing Homes: The Residents' View." Age and Ageing (2007) 36: 197-202 at 197; McSteen, K., Peden-McAlpine, C. "The Role of The Nurse as Advocate in Ethically Difficult Care Situations With Dying Patients." Journal of Hospice and Palliative Nursing [Online] (2006) 8 (05); Watson, J., Hockley, J., Dewar, B. "Barriers to Implementing an Integrated Care Pathway for The Last Days of Life in Nursing Homes." International Journal of Palliative Nursing (2006) 12 (6) 234-240 at 238.

³ Participant Three, Four, Seven, Eight.

⁴ Participant Three, Four, Seven, Eight.

⁵ Daaleman, T., Usher, B., Williams, S., Rawlings, J., Hanson, L. "An Exploratory Study of Spiritual Care at The End of Life." Annals of Family Medicine [Online] (2008) 6 (5). Gray, B. "The Emotional Labour of Nursing – Defining and Managing Emotions in Nursing Work." Nurse Education Today (2009) 29: 168-175 at 170.

⁶ Participants Five, Six, Seven, Eight.

⁷ Costello, J. "Dying Well: Nurses' Experiences of 'Good and Bad' Deaths in Hospital." Journal of Advanced Nursing (2006) 54 (5) 594-601 at 596; Kayser-Jones, J. "The Experience of Dying: An Ethnographic Nursing Home Study." The Gerontologist (2002) 42: 11-19 at 15-16. Costello, J., "Dying Well: Nurses' Experiences of 'Good and Bad' Deaths in Hospital." Issues and Innovations in Nursing Practice (2005) November, 594-601 at 595.

Although, the participants did not receive any direct requests for euthanasia from the patients, one participant did find it difficult to determine what an exhausted patient's request to be "pain-free" meant.⁸ Mental suffering and fear is regarded as being a possible reason for requesting euthanasia and this may arise because of poor symptom management, feelings of being alone or abandoned and fear of a painful death, especially if the patient is terminally ill and undergoing pain medication management.⁹ The participants felt that the patient's fear would have a significant negative impact on the trusting relationship between nurse and patient and disrupt the peaceful and dignified death that they wished to achieve.¹⁰ Asch's research further reveals that, if fear is a primary emotion within the dying process, there is a great risk that, if euthanasia were legal, the patient would have an added fear of euthanasia being imposed without consent.¹¹ Gentle probing of the patient's real needs often means that euthanasia is no longer an issue.¹²

5.2.2 The Role of Physical Suffering

As the participants discovered, physical pain and accompanying fatigue which can cause depression can also interfere with the patient's ability to function normally at the end of life and this is often caused by the impact of pain-relieving medication and

⁸ Participant Three.

⁹ Participants One, Two, Six; Mystakidou, K., Parpa, E., Katsouda, E., Galanos, A., Vlahos, L. "Pain and Desire for Hastened Death in Terminally Ill Cancer Patients." *Cancer Nursing* (2005) 28 (4) 318-324 at 319; Back, A., Young, J., McCown, E., Engelberg, R., Vig, E., Reinke, L., Wenrich, M., McGrath, B., Curtis, J. "Abandonment at The End Of life From Patient, Caregiver, Nurse and Physician Perspectives." *Archives Internal Medicine* (2009) 169 (5) 474-479 at 476.

¹⁰ Participants Four, Five, Seven, Nine.

¹¹ Asch, David A. "The Role of Critical Care Nurses in Euthanasia and Assisted Suicide." *The New England Journal of Medicine* [Online] (1996) 334 (21).

¹² Verpoort, C., Gastmans, C., Dierckx de Casterlé, B. "Palliative Care Nurses' Views on Euthanasia." *Journal of Advanced Nursing* (2004) 47 (6) 592-600 at 595; Houtepen, R., Hendrikx, D. "Nurses and The Virtues of Dealing With Existential Questions in Terminal Palliative Care." *Nursing Ethics* (2003) 10 (4) 377-388 at 378, 383-384.

body system shutdown.¹³ Where relatives became involved in the decision-making related to further medical intervention, conflict sometimes arose between the patient, relatives and doctor, especially where the patient had involved the participants in confidences about their final wishes, but had not shared the information with the relatives.¹⁴ This posed difficult challenges for the participants, especially where relatives, who were experiencing considerable emotional turmoil watching their loved one suffering, clung onto the hope that the patient was not dying and demanded treatment which the participants considered disproportionate to the outcome of the patient's impending death.¹⁵

Some participants were concerned about relatives expressing a wish that the patient would "just slip away," whilst others asked covertly that the participants would hasten the patient's death, a finding similar to that in Seymour et al's European study.¹⁶ The participants were concerned that relatives may have had an ulterior motive in requesting the patient's premature death, such as financial gain and, similar to the findings in Kelly et al's, Deffner and Bell, Hunter and Smith's studies; this required skilled management on their part as they drew on their experience to work with the families in their role as advocate.¹⁷ Young and Ogden found that where nurses perceive 'suffering' as more

¹³ Participants Two, Five, Eight, Nine; Berterv, C. "Editorial: Fatigue The Most Common Problem Within People Afflicted with Cancer; Challenge for Health Care Professionals – Widening Our Perspectives on Existential Issues." Austral-Asian Journal of Cancer [Online] (2009) (8) 4.

¹⁴ Participants Two, Five, Six, Eight, Nine.

¹⁵ Participants One, Two, Three, Five, Six, Seven, Eight, Nine, Eleven.

¹⁶ Participants One, Two, Three, Five, Seven, Eight, Ten, Eleven.; Seymour, J., Janssens, R., Broeckaert, B. "Relieving Suffering at The End of Life: Practitioners' Perspectives on Palliative Sedation from Three European Countries." Social Science and Medicine (2007) 64, 1679-1691 at 1686.

¹⁷ Kelly, D., Ross, S., Gray, B., Smith, P. "Death, Dying and Emotional Labour: Problematic Dimensions of The Bone Marrow Transplant Nursing Role?" Journal of Advanced Nursing (2000) 32 (4) 952-960 at 957; Hunter, B., Smith, P. "Emotional Labour: Just Another Buzz Word?" International Journal of Nursing Studies (2007) 44, 859-861 at 860; Deffner, J., Bell, S. "Nurses' Death Anxiety, Comfort Level During Communication With Patients and Families Regarding Death, and Exposure to Communication Education: A Quantitative Study." Journal for Nurses in Staff Development [Online] (2005) 21 (91); McSteen, K., Peden-McAlpine, C. "The Role of The Nurse as Advocate in Ethically Difficult Care Situations With Dying Patients." Journal of Hospice and Palliative Nursing [Online] (2006) 8 (05).

morally wrong than hastening death, they felt that physicians should be allowed legally to practise voluntary euthanasia and assisted suicide.¹⁸ In this study, the participants did not adhere to the relative's indirect requests to help the patient die, viewing their requests as a sign of mental and physical exhaustion and an expression of their suffering.¹⁹ As evidenced in the case of Ms B, when pain, fatigue and depression are treated, the suffering is diminished and the patient's attitude can change positively.²⁰

5.2.3 Quality of Life: Dignity, Age and Incapacity.

Whilst age of the patient, disability, and dementia had some influence on decisions regarding treatment, this was usually linked to the patient's quality of life after medical intervention, although one participant intervened on behalf of an eighty-five year old lady who was not going to be treated initially, after suffering a stroke.²¹ The 'burden' of old age or incapacity did not affect the value of the patient which was not measured in terms of what they were able to contribute to society.²² This reflects Koch's view of personhood not as a condition status, but as "absolute, irrespective of qualifiers," or as Hellsten determines, where a "person" is one capable of being an autonomous moral agent with moral rights which continue when the person is incapacitated because, out of respect for human dignity, others make decisions on his/her behalf.²³

¹⁸ Young, M.G. Ogden, R.D. "End-of-Life Issues: A Survey of English-Speaking Canadian Nurses in AIDS care. *Journal of The Association of Nurses in Aids Care* (1998) 9 (2) 18-25 at 21.

¹⁹ Participants One, Two, Four, Five, Six, Seven, Eight, Ten.

²⁰ The High Court of Justice: Family Division. "Approved Judgment: Ms. B and An NHS Hospital Trust [2002] EWHC 429 (Fam)" *The Court Service – Family Division – Judgment* [Online].

²¹ Participants Two, Three, Four, Five, Six, Seven, Eight, Ten.

²² Participants Four, Six, Seven, Nine, Eleven .

²³ Koch, T. "The Difference That Difference Makes: Bioethics and The Challenge of Disability." *Journal of Medicine and Philosophy* (2004) 29 (6): 697-716 at 703; Hellsten, S. "Towards an Alternative Approach to Personhood in The End of Life Questions." *Theoretical Medicine*, (2000) 21:515-536 at 517, 531.

The participants considered 'dignity' to be imperative at the end-of-life and this was associated with the patient's right to privacy, reverence, respect, being pain-free, the participant's sensitivity to his/her uncontrolled loss of bodily functions, providing quality nursing care including skin, eye and mouth care, ensuring the patient was fed and spending time speaking to him/her.²⁴ This is similar to the findings of Kayser-Jones, where many patients experienced a loss of dignity during the last days of their lives when they faced difficulties with feeding, positioning, cleanliness, mouth care, wearing incontinent pads, cultural and communication problems, loss of respect and loss of control of their lives.²⁵ Although the participants were uncertain whether the unconscious patient did have a quality of life, 'dying with dignity' did not mean taking his/her life.²⁶

Although some decisions were based on the patient's age, the participants based their decision-making on physical condition rather than age.²⁷ Even though they tried to ensure that all patients received equity in treatment, including resuscitation, they conceded that the relative's preferred treatment for those patients with dementia would be followed, including not treating the patient.²⁸ According to the participants, society in general did not value the elderly and it was their professional duty to care for their patients, to act as their advocate, to assist the doctor and to remain unbiased and care for everyone.²⁹

²⁴ Participants One, Three, Four, Eight, Nine, Eleven.

²⁵ Kayser-Jones, "The Experience of Dying." *The Gerontologist* (2002) 42:11-19 at 16.

²⁶ Participants Six, Seven, Ten.

²⁷ Participants Two, Three, Six, Ten.

²⁸ Participants Two, Three, Five, Seven, Ten, Eleven.

²⁹ Participants One, Four, Five, Six, Nine, Ten.

5.2.4 The Role of Nurses' Intuition, Knowledge and Experience

The participants found that making decisions on end-of-life care and deciding what is in the patient's 'best interest' is a balanced process, based on, "love of the patients," information given by others, as well as conscience and belief systems, and that intuition, training, knowledge and years of experience played an important role in knowing when the patient was going to die.³⁰ They accepted that intuition was most likely a product of knowledge gained over many years, but that often they had a "gut instinct" of what treatment should be given, which was especially important when caring for patients with dementia at the end stage of life³¹ However, Smith et al. argue that, whilst training and knowledge are important aspects of ensuring that a competent practitioner is able to assess appropriately and give quality care, making decisions based on emotions such as 'intuition' and 'gut-feeling' could possibly place the patient at risk.³² One participant related that her knowledge and experience of animals, who could not verbally communicate, helped her to understand when a patient was "struggling."³³ Other participants relied on the patient's physical signs such as grimacing, or hands clenched to assess the patient's needs, but ultimately they found that "knowing the resident well" plus input from relatives and care assistants were major factors in making decisions.³⁴ However, as Moorman et al, found, relatives or surrogates rely heavily on their own preferences for end-of-life treatment when considering what their loved one would want and this may not reflect the patient's desires for end-of-life care.³⁵

³⁰ Participants One, Three, Four, Five, Nine, Ten, Eleven.

³¹ Participants, Two, Three, Six, Nine.

³² Smith, P., Pearson, P., Ross, P. "Emotions at Work: What is The Link to Patient and Staff Safety? Implications for Nurse Managers in The NHS." *Journal of Nursing Management* (2009) 17, 230-237 at 230-231, 234, 236.

³³ Participant Eleven.

³⁴ Participants One, Two, Three, Four, Five, Six, Seven, Nine, Ten, Eleven.

³⁵ Moorman, S., Hauser, R., Carr, D. "Do Older Adults Know Their Spouses' End-of-Life Treatment Preferences?" *Research in Aging* (2009) 31 (4) 463-491 at 473.

Also taken into consideration when making decisions was the patient's right to make an autonomous decision, but this created difficulties where s/he would not give consent to treatment which the participants considered necessary.³⁶ Valente's research found that patients want information so that they can determine their own care at the end-of-life and where nurses support patients' autonomy, there are perceived benefits and an overall quality of life.³⁷ However, 'autonomy' may not be an appropriate reason for decisions and, as Veerport et al's study in Belgium found, nurses who believed in respect for the patient's autonomy also accepted euthanasia, but when those nurses recognised the palliative alternatives, their views changed.³⁸

5.2.5 Positive Relationships: Trust

At the heart of the decision-making process were positive relationships based on trust and compassion, which the participants considered to be essential to the holistic care of the patient and his relatives; similar to Houtepen and Hendriks's Belgian study, they found that building trust takes time.³⁹ Telling the patient the truth in order to make appropriate end-of-life choices was an essential element of that trust for them. However, as Smith and Lorentzon caution, being totally open with the patient's prognosis may not be appropriate for all patients and, as Kayser-Jones found, some nurses may find it

³⁶ Participants, Four, Seven, Eight, Ten.

³⁷ Valente, S. "End-of-Life Challenges: Honoring Autonomy." *Cancer Nursing* [Online] (2004) 27 (4) 3; Hickman, S. "Honoring Resident Autonomy In Long-Term Care: Special Considerations." *Journal of Psychosocial Nursing and Mental Health Services* [Online] (2004) 42 (1).

³⁸ Veerport, C., Gastmans, C., Dierckx de Casterlé, B. "Palliative Care Nurses' Views on Euthanasia." *Journal of Advanced Nursing* (2004) 47 (6) 592-600 at 596-597.

³⁹ Participant Nine; Houtepen, R., Hendriks, D. "Nurses and The Virtues of Dealing With Existential Questions in Terminal Palliative Care." *Nursing Ethics* (2003) 10 (4) 377-388 at 380.; Mok, E., Chui, P. "Nurse-Patient Relationships in Palliative Care." *Journal of Advanced Nursing*, (2004) 48 (5) 475-483 at 479.

stressful to communicate with elderly patients on important key issues related to dying.⁴⁰

5.2.6 Emotional Turmoil

The participants recognised the emotional turmoil in communicating with the elderly patients and their relatives, but viewed nursing care as being distinct from medical care and which included emotional support and practical help to relatives and friends as well as providing “tender loving care” and “cuddles” to the patients.⁴¹ They perceived themselves as being expected by others to possess essential qualities such as compassion, understanding, patience, empathy and a genuine caring for the patient, as well as a sense of humour.⁴² They also experienced negative emotions, especially where they were blocked from making decisions by a doctor and at times they were unhappy with the outcome for the patient.⁴³ If there was conflict, they would strive to resolve this so that the patient would benefit; however, conflict and nurses’ feelings of inferiority to a doctor resulted in confrontation, anger and, at times, feelings of intimidation, especially when doctors adopted “the old school” attitude and expected the participants to carry out his orders without question.⁴⁴ These findings reflect Gray and Smith’s research that, nurses experience negative emotions such as “anger” and “despair” in some situations and because of others’ expectations of them, they perceive that they are not allowed to show their frustration and have to “sit on” their frustrations, with resulting “burn-out.”⁴⁵ Coping mechanisms, such as a sense of humour, helped the

⁴⁰ Participants Six, Ten; Smith, P., Lorentzon, M. “Is Emotional Labour Ethical?” *Nursing Ethics* (2005) 12 (6) 638-642 at 640; Kayser-Jones, J. “The Experience of Dying: An Ethnographic Nursing Home Study.” *The Gerontologist* (2002) 42: 11-19 at 18.

⁴¹ Participants Two, Six, Seven, Eight, Eleven.

⁴² Participants Four, Six, Seven, Eight, Nine, Ten.

⁴³ Participants Two, Five, Six, Ten.

⁴⁴ Participants Seven, Eight, Ten.

⁴⁵ Gray, B., Smith, P. “Emotional Labour and The Clinical Settings of Nursing Care: The Perspectives of Nurses in East London.” *Nurse Education in Practice* (2009) 9, 253-261 at 258.

participants to deal with the difficulties, but, as Gray suggests, often these are only a means to suppress the many emotions that remain 'invisible' in nursing, considered by some senior staff as a weakness, and which results in the burden known as "emotional labour."⁴⁶ The participants found doctors often detached from the emotions involved in patient care and left them to deal with the difficulties.

Saying goodbye in death to a cherished patient was also difficult for the participants and they developed a support system to help each other cope with their grief and loss, including 'time out' for a cup of tea and a cigarette or attending the patient's funeral.⁴⁷ Over the years, they had built intimate relationships with their patients and losing them was akin to losing a friend, especially those with dementia who were totally dependent on their care.⁴⁸ Gray and Smith discovered that nurses found it difficult not to take their emotions home with them and they usually end up talking about their patients and feeling very stressed.⁴⁹ The participants developed their own individual strategies to cope with the patient's death, especially when performing the last offices, talking to him/her as if s/he was alive, leaving the light on in the room, opening the window to "let the spirit out", not covering the face.⁵⁰ As well as coping with their own grief, the relatives' grief, manifesting in aggression, criticism or unusual behaviour often proved a difficult emotional burden for the participants, leaving them feeling distraught and, at times, questioning their practice.⁵¹ As Kirchoff and Beckstrand discovered, nurses strive to manage their own, the patients' and relatives' emotions and come to terms with the

⁴⁶ Participants Seven, Eight, Ten.; Gray, B. "The Emotional Labour of Nursing – Defining and Managing Emotions in Nursing Work." *Nurse Education Today* (2009) 29: 168-175 at 171; Smith, P., Pearson, P., Ross, P. "Emotions at Work: What is The Link to Patient and Staff Safety? Implications for Nurse Managers in The NHS." *Journal of Nursing Management* (2009) 17, 230-237 at 235.

⁴⁷ Participants One, Seven, Eight.

⁴⁸ Participants Two, Five, Eleven.

⁴⁹ Gray, B., Smith, P. "Emotional Labour and The Clinical Settings of Nursing Care: The Perspectives of Nurses in East London." *Nurse Education in Practice* (2009) 9, 253-261 at 257.

⁵⁰ Participants Four, Eight.

⁵¹ Participants One, Seven, Eight.

difficult processes that are often completely unavoidable in everyday patient care which can prevent nurses from providing quality care.⁵²

5.3 The Provision of Nutrition and Hydration at The End of Life

The majority of care homes did not provide for the administration of intravenous fluids, since this was usually administered in a general hospital, although, some did provide for the administration of subcutaneous fluids. The participants found that, if the patient could communicate his/her needs, provision of artificial hydration would be prescribed by doctors, but this depended on whether the patient wished to remain in the care home and receive subcutaneous fluids, which the participants regarded as an effective way of receiving hydration, or be admitted to hospital where intravenous fluids would be administered. If the patient's swallowing reflexes diminished, the participants informed the relatives that decisions would need to be made as to whether fluids would be beneficial for the patient or not and, if they wished the patient hydrated artificially, arrangements could be made to admit him/her to hospital.⁵³ This can be problematic where doctors perceive ANH as an added physical and psychological burden to the patient at the end of life and the withholding or removal as such perceived by relatives and nurses as promoting the patient's death, even in the terminal phase.⁵⁴ It is not uncommon for nurses working in care homes to provide the patient with his/her favourite food purchased from outside the care home and, as found in Van der Riet et al's research, the provision of nutrition and hydration is associated by nurses and families as being linked to "compassion and nurturing" a symbol of providing life, and

⁵² Kirchoff, K., Beckstrand, L. "Critical Care Nurses' Perceptions of Obstacles and Helpful Behaviors in Providing End-of-Life Care to Dying Patients." American Association of Critical Care Nurses [Online] (1998).

⁵³ Participants Five, Seven.

⁵⁴ Van der Riet, P., Good, P., Higgins, I., Sneesby, L. "Palliative Care Professionals' Perceptions of Nutrition and Hydration at The End Of Life." International Journal of Palliative Nursing (2008) 14 (3) 145-151 at 148, 149.

dehydration linked to suffering and abandoning the patient.⁵⁵ Abandoning a patient who would not eat was not an option for one participant, stating that she “had to interfere” and stop the process by referring him for admission to hospital, ensuring optimum hydration and nutrition would be given.⁵⁶

If the patient could not communicate his needs, for example, where the patient had a stroke, it was generally regarded as futile to make provision for any form of ANH, although one participant opted to ensure fluids were given.⁵⁷ Relatives were consulted, but the patient would be deprived of hydration, even where a subcutaneous infusion could be given, if that was what the relatives wished or where the patient refused treatment.⁵⁸ On one occasion, however, one participant noticed that the relatives’ intervention had meant that subcutaneous fluids were given and the patient had rallied.⁵⁹ The same participant considered futile the administration of ‘PEG’ tubes and unnecessary.⁶⁰ Bryon found that where nurses in the clinical area argue on the one hand that ANH are basic nursing care at the end of life, even for those patients with dementia, against those who consider that this would diminish quality of life and a dignified death this can create an ethical dilemma for the nursing team.⁶¹ As one participant indicated, she would feel compromised if the patient gave a directive not to give hydration by any means at the end of life.⁶² The experiences of nurses in Van der Riet et al study was

⁵⁵ Ibid., at 148; Participant One.

⁵⁶ Participant One.

⁵⁷ Participant One. Two, Seven.

⁵⁸ Participant Seven.

⁵⁹ Participant Five.

⁶⁰ Percutaneous Endoscopic Gastrostomy (PEG).

⁶¹ Bryon, E., Dierckx de Casterlé, B., Gastmans, C. “Nurses’ Attitudes Towards Artificial Food or Fluid Administration in Patients with Dementia and in Terminally Ill Patients: A Review of The Literature.” *Journal of Medical Ethics* (2008) 34 [Online].

⁶² Participant Two.

that, where patients were dying naturally, as long as adequate mouth care was given, they did not appear to suffer.⁶³

5.4 The Provision of Medication at The End of Life.

Where decisions were made on whether or not to give medication, some participants depended on their professional experience to assess the patient, whilst others used a pain assessment tool. Doctors often relied on the participant's recommendation to determine whether to prescribe pain-relieving drugs or otherwise; however, the participants perceived doctors as being more knowledgeable than nurses and, as one participant explained, she would not contest a doctor's decision on medication dose.⁶⁴ If there was any query regarding medication dose, in general the participants would involve the opinion of a colleague and/or another doctor. This is not surprising since, as Phillips et al discovered, many nurses working in residential care homes are unsure whether the use of strong pain medication can contribute to the patient ceasing to breathe and Reid et al. found that many perceived dose increments would lead to sedation and then cause death.⁶⁵ However, one participant would request a transfer from the care home if she disagreed with the prescribed care or treatment.

Where the patient appeared to experience severe pain at the end stages of life, the participant would make a decision based on her "feelings" and sometimes with the aid of an assessment tool, whether or not to administer additional (prescribed) pain-

⁶³ Van der Riet, P., Good, P., Higgins, I., Sneesby, L. "Palliative Care Professionals' Perceptions of Nutrition and Hydration at The End Of Life." International Journal of Palliative Nursing (2008) 14 (3) 145-151.

⁶⁴ Participant Eleven.

⁶⁵ Phillips, J., Davidson, P., Ollerton, R., Jackson, D., Kristjanson, L. "A Survey of Commitment and Compassion Among Nurses in Residential Aged Care." International Journal of Palliative Nursing (2007) 13 (6) 282-290 at 284; Reid, C.M., Gooberman-Hill, R., Hanks, G.W. "Opioid Analgesics for Cancer Pain: Symptom Control for the Living or Comfort for the Dying? A Qualitative Study to Investigate the Factors influencing the Decision to Accept Morphine for Pain Caused by Cancer." Annals of Oncology (2008) 19 (1) 44-48.

relieving medication to a patient.⁶⁶ One participant stated she would administer prescribed diamorphine because the patient's apparent agitation would alarm the friends, but in general the participants found it more difficult to assess the level of pain in those patients with dementia or who were unconscious, relying on facial expressions or "restlessness and agitation" which was perceived as a sign of the patient experiencing pain.⁶⁷ However, as Watson et al.'s study revealed, nurses often lack knowledge of palliative care drugs and in controlling end-of-life symptoms and find it difficult to distinguish between pain and agitation, assuming that dying in itself is painful.⁶⁸ Veepoort and Gastmas found that nurses often view the use of palliative sedation, as hypocritical and as a form of euthanasia, since, in their opinion, the use of such is intended to reduce the consciousness of the patient and release him from suffering.⁶⁹ However, Seymour et al.'s research revealed that palliative sedation is normally used to relieve the symptoms of "delirium, agitation and dyspnoea in the terminally ill" and not to relieve pain and, therefore, suffering, which is treated with analgesia.⁷⁰

The research conducted here found, as did Seymour et al's European study, that relatives would make a request to increase pain-relieving medication, but with the purpose of hastening the patient's death.⁷¹ Being conscious of their accountability in law, especially since the Shipman enquiry, the participants assessed the requirement for

⁶⁶ Participant One, Two, Three, Four, Five, Six, Eight.

⁶⁷ Participants One, Nine, Eleven.

⁶⁸ Watson, J., Hockley, J., Dewar, B. "Barriers to Implementing an Integrated Care Pathway for The Last Days of Life in Nursing Homes." International Journal of Palliative Nursing (2006) 12 (6) 234-240 at 236.

⁶⁹ Verpoort, C., Gastmans, C., Dierckx de Casterlé, B. "Palliative Care Nurses' Views on Euthanasia." Journal of Advanced Nursing (2004) 47 (6) 592-600 at 596.

⁷⁰ Seymour, J., Janssens, R., Broeckaert, B. "Relieving Suffering at The End of Life: Practitioners' Perspectives on Palliative Sedation from Three European Countries." Social Science and Medicine (2007) 64: 1679-1691 at 1681.

⁷¹ Ibid., at 1686; Participant Seven.

any increase in pain-relieving medication carefully and would administer this, even if a possible side-effect could be the shortening of the patient's life.⁷² Costello found that, where patients die in pain or with unrelieved suffering, nurses experience guilt and a sense of failure.⁷³

When relatives resisted one participant's decision to give morphine for pain relief, requiring her to ask their permission one participant felt compromised professionally and whilst another participant resorted to 'persuasion' to agree with her decision, she would have acceded to the relative's wishes even if she disagreed with them.⁷⁴ In order to circumnavigate the problem and gain consent from the relatives to increase the medication dose or frequency, they would modify their language and suggest that "things aren't going as well as they were; we don't think we are keeping on top of her pain." Gaining consent from the patient was considered both important and at times challenging, where the patient would refuse pain-relieving medication, not wishing to lose control due to drowsiness and this sometimes caused conflict between the patient and nurse.⁷⁵ This finding is similar to that in McSteen and Peden-McAlpine study, which revealed that decision-making can be hindered by the perceptions of all those involved (patient, family, staff) of when it is appropriate to give pain relief.⁷⁶ In addition, opioid acceptability is often complicated by the patient's interpretation of pain, other symptoms of his illness and medication side-effects.⁷⁷

⁷² Participant One, Five, Eleven.

⁷³ Costello, J. "Dying Well: Nurses' Experiences of 'Good and Bad' Deaths in Hospital." *Journal of Advanced Nursing* (2006) 54 (5) 594-601 at 598-599.; *The Shipman Inquiry* (Crown Copyright 2001) [Online].

⁷⁴ Participant Four, Six.

⁷⁵ Participant Seven.

⁷⁶ McSteen, K., Peden-McAlpine, C. "The Role of The Nurse as Advocate in Ethically Difficult Care Situations With Dying Patients." *Journal of Hospice and Palliative Nursing* [Online] (2006) 8.

⁷⁷ Reid, C.M., Gooberman-Hill, R., Hanks, G.W. "Opioid Analgesics for Cancer Pain: Symptom Control for the Living or Comfort for the Dying? A Qualitative Study to Investigate the Factors influencing the Decision to Accept Morphine for Pain Caused by Cancer." *Annals of Oncology* (2008) 19 (1) 44-48.

5.5 Conclusion

Empirical studies of death and dying generally focus on what is perceived as a good death involving symptom control, in hospital or hospice settings. This research contributes a different perspective based on the experiences of a group of nurses working in care homes for the elderly situated in farming communities, coastal towns and cities with their own unique views and traditions, based in the north of Scotland.

Although the cultural context of studies in the Netherlands, Belgium, Austria, USA and Australia differ from that in the United Kingdom, there are many similarities to the findings in this empirical research and to that found in international studies, as well as other UK studies, (Seymour (part UK), Gray and Smith, Watson, Costello, Kelly et al., Hunter and Smith, Deffner and Bell, Smith et al.).

In this research study, the caring ethos of the care home is perceived as strengthening the emotional bond between patient and nurse and contributing to the patient dying with dignity. The patient's age and incapacity were perceived positively and did not diminish his/her value as a living being. The nurse's role in providing care for patients suffering mentally and physically was recognised as being important to ensure that the patient died peacefully. Decisions on end-of-life care were based on intuition, knowledge and experience, nurses' belief systems and conscience, relatives' and doctors' input and trust between all concerned. Emotional labour resulted from dealing with difficult situations involving the patient, the doctor and the relatives, especially related to the provision of nutrition and hydration artificially (ANH), pain-relieving medication and

indirect requests to hasten the patient's death. Coping mechanisms included their own unique traditions of dealing with the patient's death.

In chapter seven, these findings will be discussed in the light of Christian moral principles.

CHAPTER SIX

MORAL PHILOSOPHY AND THEOLOGY LITERATURE

6.1 Introduction

In order to meet the aim of the study, the findings from the empirical research will be discussed in the light of Christian moral principles, Christians being the dominant religious group in the United Kingdom, from which the law is derived.¹ This chapter presents an exposition of doctrinal teachings and their implications for nurses who are Christian Catholics in relation to end-of-life decision making and euthanasia. The chapter will be divided into three parts a) Euthanasia, b) Withdrawing and withholding artificial nutrition and hydration, c) Questions of co-operation and of conscientious objection.

6.2 Euthanasia: A Presentation of Magisterial Teaching

6.2.1 Papal Magisterium: ‘Evangelium vitae’.

The Papal encyclical ‘Evangelium vitae’ (The Gospel of Life), is the highest level of Magisterial teaching addressing euthanasia because it is given by the Pope himself as a teaching document.² Death is a natural part of life and its inevitability is something all humans are called to accept, but death is sometimes seen as a “senseless” interruption to a meaningful life or it becomes a “rightful liberation” to free the person from pain and suffering, where euthanasia is perceived as a solution to end that suffering.³ Involuntary euthanasia can be justified for utilitarian motives, to remove the weakest non-productive members from society, such as the elderly, the severely disabled and the terminally ill.⁴

¹ Office for National Statistics. “Religious Populations: Christianity Is Main Religion in Britain” [Online] (2004).

² *Evangelium vitae*, n.1.

³ *Ibid.*, nn. 15, 64,

⁴ *Ibid.*, nn. 15, 66.

With advances in medicine and the ability to prolong and sustain life, there is a temptation to control death and bring it about “gently” before its time, thus euthanasia becomes,

“an action or omission which of itself and by intention causes death, with the purpose of eliminating all suffering.”⁵

Euthanasia should not be confused with a decision to forego medical treatment which may be disproportionate to any realistic results.⁶ Where a person is dying and death is imminent and inevitable, so long as the normal care due to him/her is not interrupted, the patient may refuse forms of treatment that could be burdensome in prolonging his/her life.⁷ Similarly, it is permissible to use painkillers and sedatives, even at the risk of shortening life, but without depriving the patient of consciousness, which is not neither euthanasia nor suicide, but a desire to ease pain effectively by using the medicine that is available.⁸ Taking into account all these issues, John Paul II, formally proclaimed,

“I confirm that euthanasia is a grave violation of the law of God, since it is the deliberate and morally unacceptable killing of a human person.”⁹

John Paul II wrote that, euthanasia is a “false mercy,” whereas true compassion leads to sharing another’s pain whilst caring for him with patience and love.¹⁰ Suicide is regarded as serious as murder, but there are certain conditions which can lessen or remove subjective responsibility, such as a person’s psychological state, his/her cultural practice, or social conditioning.¹¹ Those who co-operate or assist someone with suicide

⁵ Ibid., nn. 64, 65.

⁶ Ibid., n.65.

⁷ Ibid., n. 65.

⁸ Ibid., n. 65.

⁹ Ibid., n.65

¹⁰ Ibid., n. 66.

¹¹ Ibid., n. 66.

perpetrate an injustice, even where the person requests help to die.¹² Some proponents of euthanasia demand to exercise their right as citizens to request an ending of a life, safely, freely and with assistance from medical personnel.¹³ They state that it is not the task of the law to choose between different moral opinions, but in a modern and pluralistic society, people should have the freedom to dispose of their own lives.¹⁴ Some claim that there are some lives more valuable than others, others, that the law should always express the majority view and the will of the people.¹⁵

6.2.2 Papal Magisterium: Other Interventions

The declaration of the Congregation for the Doctrine of the Faith ‘*Jura et bona*’ reaffirms the Church’s teaching that human life is the basis of all goods and that no-one can dispose of it at will.¹⁶ Intentional killing of self is equated with intentional killing of others, regarded as murder.¹⁷ The teachings of John Paul II in the encyclical ‘*Evangelium vitae*’ repeats the definition of euthanasia as being a “mercy-killing,” but ‘*Jura et bona*’ emphasises that:

“euthanasia’s terms of reference are to be found in the intention of the will and in the methods used.”¹⁸

It also clearly states that “nothing and no-one can in any way permit the killing of an innocent human being.”¹⁹

Christian suffering is perceived as having a special place in God’s saving plan, a sharing in Christ’s passion.²⁰ However, physical suffering can affect the person psychologically

¹² *Ibid.*, n. 66

¹³ *Ibid.*, n.68.

¹⁴ *Ibid.*, n.68.

¹⁵ *Ibid.*, n.68.

¹⁶ *Jura et bona*, 511.

¹⁷ *Ibid.*, 512.

¹⁸ *Jura et bona*, 512; *Evangelium vitae*, n. 65.

¹⁹ *Jura et bona*, 512.

to a point where he can no longer endure pain and may wish to remove that pain at any cost, including requesting euthanasia.²¹ The intention to relieve pain effectively, even at the risk of shortening the patient's life, but where death is neither sought nor intended, is not euthanasia.²² In addition, the patient has a right to forego and is never obliged to use medical treatment which is extraordinary means.²³ Judgments on which treatments to be used are calculated on the basis of what the patient can tolerate, their degree of complexity or risk, their cost, and this is compared with the results that can be expected, a measure to enable the patient to be given the right treatment without any undue burdens.²⁴ However, it is never permissible to kill a person because of his/her alleged quality of life.²⁵

When considering the 'quality of life' to be saved, the Church teaches that it is the "sacred character of life" which must be considered at all times.²⁶ The sick or handicapped deserve special respect and to end their lives by direct euthanasia is morally unacceptable.²⁷ Although the doctor is not morally obliged to provide extraordinary means to preserve that life, there is a danger that his subjective view of the patient's "quality of life" may not take into account all the relevant treatments that

²⁰ Ibid., 513 ; Evangelium vitae, n. 67.

²¹ Ibid., 513 ; Evangelium vitae, n. 67.

²² Jura et bona, 513, 514; Pius XII, The Attempt on Innocent Human Life (26 November 1951), *The Human Body: Papal Teachings*, p. 182 in O'Rourke, K., Boyle, P. Medical Ethics: Sources of Catholic Teachings, 3rd. ed., (Georgetown University Press, Washington, 1999) 315; Pius XII, The Prolongation of Life (1957) 361.

²³ Jura et bona 515-516; Evangelium vitae, n.65.

²⁴ Jura et bona, 515.

²⁵ Ibid., 515.

²⁶ Pontifical Council Cor Unum, Questions of Ethics Regarding The Fatally Ill and The Dying, Vatican Press, 1981, pp.8-9 in O'Rourke, K., Boyle, P. Medical Ethics: Sources of Catholic Teachings, 3rd ed. (1999) 220.

²⁷ CCC, nn. 2276, 2277.

could be offered to him.²⁸ Therefore, there is a strict obligation to provide what is called “minimal” therapeutic measures and also hydration and nutrition.²⁹

6.2.3 Bishops from The United States, Ireland, England and Wales, Scotland.

In 1969, Louis Kutner, an American lawyer, first proposed the advance directive or “living-will,” as an appropriate way of interpreting the patient’s intentions in the future.³⁰ However, the United States Catholic Bishops state that legislation should always pre-suppose the right to life of every human being and should reflect the patient’s moral responsibility to request reasonable treatment, his right to refuse treatment, as well as recognising the presumption of ordinary care such as hydration and nourishment.³¹ An “ordinary” means of preserving life is that means which can effectively preserve life without imposing any excessive burdens on the patient, an “extraordinary means” is that means which provides no benefit or imposes too great a burden on the patient.³² For this reason, life-sustaining technology should be evaluated in the light of the Christian meaning of life to ensure that it is neither a burden to the patient nor that it is withdrawn with the intention of causing death.³³ The Michigan

²⁸ Pontifical Council Cor Unum, Questions of Ethics Regarding The Fatally Ill and The Dying, Vatican Press, 1981, pp.8-9 in O’Rourke, K., Boyle, P. Medical Ethics: Sources of Catholic Teachings, 3rd ed. (1999) 220.

²⁹ Ibid., 220.

³⁰ Kutner, L. “Due Process of Euthanasia: The Living Will, A Proposal.” Indiana Law Journal (1969) 539-554 at 550-554.

³¹ United States National Conference of Catholic Bishops Committee for Pro-Life Activities, Guidelines for Legislation on Life-Sustaining Treatment (10 November 1984), *Origins* 14: no. 32, Jan. 24, 1985, pp. 526-528 in O’Rourke, K., Boyle, P. Medical Ethics: Source of Catholic Teachings, 3rd ed, (Georgetown University Press, Washington, 1999) 241-243 at 243.

³² United States National Conference of Catholic Bishops Committee for Pro-Life Activities, Statement on Uniform Rights of The Terminally Ill Act (20 March 1986), *Origins* 16: no. 12, Sept. 4, 1986, pp. 222-224 in O’Rourke, K., Boyle, P., Medical Ethics: Sources of Catholic Teachings, 3rd. ed. (Georgetown University Press, Washington, 1999) 282.

³³ United States National Conference of Catholic Bishops, “Ethical and Religious Directives for Catholic Health Care Services,” *Origins* 24: no. 27 (Dec. 15, 1994), pp. 450-462 in O’Rourke, K., Boyle, P., Medical Ethics: Sources of Catholic Teachings, 3rd. ed. (Georgetown University Press, Washington, 1999) 142.

Bishops state that euthanasia can open the door to potential abuse against the most vulnerable and that suicide and assisted suicide are always morally wrong.³⁴

The Catholic Bishops' Conference of England and Wales and the Linacre Centre, in response to the "Draft Mental Incapacity Bill" also consider that there are ineffective safeguards against suicide and homicide by omission and that many decisions relating to the patient were not particularly based on his "best interests," but dependent on "past wishes and feelings."³⁵ According to them, advance directives did not solve this problem, since there is always the risk that the patient did not have adequate information at that time, especially in relation to pain management and ANH and relatives were often given power to make decisions without being accountable.³⁶

The Catholic Bishops of England and Wales also express concern that the contemporary trend of demanding a right to "die with dignity" is a demand for a right to be killed on request.³⁷ Their view is that the intentional killing of another person, such as giving high doses of medication, even where they may have requested it, is not acceptable, nor is the withdrawal of ANH or other life-sustaining treatment, in order that the patient dies.³⁸ Respect for dignity must include respect for someone's life and without that life there can be no dignity.³⁹ The Scottish Bishops' Conference make the same distinction that those who are terminally ill do not need to use extraordinary means to stay alive

³⁴ Michigan Bishops, "Living and Dying According to The Voice of Faith," *Origins* 27: no. 19 (Oct., 23, 1997), pp. 318-321 in O'Rourke, K., Boyle, P. *Medical Ethics: Sources of Catholic Teachings*, 3rd ed. (Georgetown University Press, Washington, 1999) 72.

³⁵ The Linacre Centre for Healthcare Ethics, "Response to The Draft Mental Incapacity Bill, A Joint Submission by The Catholic Bishops' Conference of England and Wales and the Linacre Centre for Healthcare Ethics" [Online] (2003).

³⁶ *Ibid.*

³⁷ Catholic Bishops' Conference of England and Wales. "Cherishing Life: Suicide and Euthanasia" [Online] (2004) nn 180-194 at 183.

³⁸ *Ibid.* 185.

³⁹ *Ibid.*, at 184.

and that it is legitimate to use painkillers even at the risk of shortening life, but not as a means to euthanasia.⁴⁰ The Irish Bishops' Committee for Bioethics also state that pain management and psychosocial support can increase the patient's feeling of well-being, remove depression and this often diminishes the desire for death and can be achieved through palliative care.⁴¹

In valuing the dignity of every life, the Catholic Church opposes the death penalty since this may contribute further to erosion of respect for life in society; however, in some 'extreme' situations it does not exclude the death penalty.⁴² In addition the legitimate defence against an unjust aggressor is perfectly reasonable even if the aggressor is killed, provided only proportionate force is used.⁴³

6.2.4 Contributions from a Christian Perspective: Questions about Concepts and Boundaries Relating to Euthanasia.

Mahoney posits the question, "If euthanasia is a benefit to a patient, why should it be limited only to those capable of requesting it?"⁴⁴ One view is that, if voluntary euthanasia were legalised, the request might not be genuine and legalisation could open the practice to involuntary euthanasia and potential abuse of the most vulnerable; Mahoney acknowledges that abuses can only be controlled to a certain extent.⁴⁵ Although Cahill suggests that limiting euthanasia to being only voluntary might prevent abuse, the patient's 'autonomy' would then become a moral guide in a request for

⁴⁰ Catholic Bishops Conference of Scotland. "Euthanasia" [Online] (27 August 2008).

⁴¹ Irish Bishops' Committee for Bioethics. "End of Life Care: Ethical and Pastoral Issues" [Online] (2002).

⁴² New Mexico Bishops, *An Opportune Time to Review The Correctional System*, *Origins* 26: no. 36 (27 February 1997), pp. 586-88 in O'Rourke, K., Boyle, P., *Medical Ethics: Sources of Catholic Teachings*, 3rd. ed. (1999) 85-86 at 85; CCC. n. 2267; *Evangelium vitae*, n. 56.

⁴³ CCC. n. 2266.

⁴⁴ Mahoney, J. *Death and Dying* (Sheed & Ward Ltd., London, England, 1984) 40-41.

⁴⁵ *Ibid.*, 41; Fitzpatrick, F. *Ethics in Nursing Practice* (1988) 189.

euthanasia.⁴⁶ This could create difficulties, for as Curran points out, ‘autonomy’ can become a selfish autonomy where the individual pursues personal selfish, narrow goals and, since humans do not live in isolation, they have obligations to others.⁴⁷

Kaveny also points out that, physician-assisted suicide and voluntary euthanasia are not ‘private choices,’ but choices that require the involvement of members of the medical profession.⁴⁸ She and Paris express concern that, where freedom and personal autonomy are respected more than life itself, physicians will inevitably acquiesce in the demands for assisted suicide and euthanasia and this would change their traditional role as healers.⁴⁹ This could eventually impact on the patient/doctor relationship where confidence in discussing end-of-life issues could be eroded with the fear of being guided to ending one’s life prematurely.⁵⁰ Kaveny examines ‘the right to refuse treatment’ and explains that this was designed to protect patients from being forced to receive medical treatment, in the name of medical science, without their consent.⁵¹ She claims this is not giving the patient the “right to die,” but the right to live without being burdened by unwanted medical treatment, even though, in some cases, this may result in hastening the patient’s death.⁵²

⁴⁶ Cahill, L., “Bioethical Decisions to End Life.” *Theological Studies* (1991) 52, 107-127 at 122.

⁴⁷ Curran, C.E. *Moral Theology: A Continuing Journey* (1982) 70-71, 117.

⁴⁸ Kaveny, M. “Assisted Suicide, Euthanasia, and The Law.” *Theological Studies* (1997) 58: 124-148 at 134.

⁴⁹ Paris, J., “Active Euthanasia.” *Theological Studies* (1992) 53: 113-126 at 118, 119. [John Paris, S.J.]; Kaveny, M. “Assisted Suicide, Euthanasia, and The Law.” *Theological Studies* (1997) 58: 124-148 at 134.

⁵⁰ Kaveny, M. “Assisted Suicide, Euthanasia, and The Law.” *Theological Studies* (1997) 58: 124-148 at 135; Finnis, J. “Euthanasia, Morality, and Law: Harry B. Burns Lecture, Loyola Marymount Law School, Los Angeles, California.” [Online] (1996) November 22.; Keenan, J. “Assisted Suicide and The Distinction Between Killing and Letting Die.” *Catholic Medical Quarterly* [Online] (1992) May ed.; Fitzpatrick, F. *Ethics in Nursing Practice* (1988) 189.

⁵¹ Kaveny, M. “Assisted Suicide, Euthanasia, and The Law.” *Theological Studies* (1997) 58: 124-148 at 129.

⁵² *Ibid.*, at 130.

Keenan's view, is that, the distinction between killing and letting die is morally ambiguous, but to those who advocate euthanasia, 'letting die' is a licit form of euthanasia and emotionally acceptable, compared to killing someone directly by assisted suicide.⁵³ Cahill, however, contests that there is a morally relevant distinction between killing people that is, choosing death for its own sake and declining life-support measures, where the outcome of death may be foreseen, but not the primary intention.⁵⁴ She argues that it is not always wrong to intend death if this is for the good of the patient and where death may relieve the patient from suffering.⁵⁵ According to her, the difficulty lies in whether the physician should be involved in a 'mercy-killing,' even though it would appear to be justified.⁵⁶

Keenan examines three "rights" arguments against euthanasia, the first, that "directly killing a patient violates the divine law," but concedes that this argument would only appeal to those who believe in the existence of God and, therefore, would only apply to Christians.⁵⁷ The second, that "natural law prohibits the direct killing of the innocent," is difficult, in that it is interpreted as a prohibition against attacking the vulnerable who cannot defend themselves. His view is that this would not apply to those who request assisted suicide on the grounds of autonomy, arguing that they are not in need of protection.⁵⁸ The third that "we have the right to do with our person as we will," is, he argues, to give the person (administering euthanasia) the right to kill us and that means giving that person the power to remove our freedom once and for all.⁵⁹ Each "right"

⁵³ Keenan, J. "Assisted Suicide and The Distinction Between Killing and Letting Die." Catholic Medical Quarterly [Online] (1992) May edition.

⁵⁴ Cahill, L., "Bioethical Decisions to End Life." Theological Studies (1991) 52 107-127 at 120-121.

⁵⁵ Ibid., 121.

⁵⁶ Ibid. 122.

⁵⁷ Keenan, J. "Assisted Suicide and The Distinction Between Killing and Letting Die." Catholic Medical Quarterly [Online] (1992) May edition.

⁵⁸ Ibid.

⁵⁹ Ibid.

applies to different moral perspectives and denies the patient the 'right' to be killed, thus demonstrating the competing interests of different viewpoints in a pluralistic society.

However, as K. Kelly points out, "rights" are meaningless without corresponding claims or obligations.⁶⁰ His view is that life may be a foundational good, but that there are other goods within our life-style and social interaction that make up the quality of our lives.⁶¹ Without love and friendship and in a wider context, good health and a feeling of well-being, life for the individual may not be worth living and the patient's choices on treatments and their effects may reflect that outlook on life.⁶²

According to Meilaender, what is extraordinary treatment for one person or a burden too great to bear, is not necessarily so for another person and those who refuse treatment may not be expressing a wish to die, but choosing how to live, even if that life is shorter.⁶³ His view is that quality of life judgments may be inappropriate for dependent incapacitated patients and that we should not impose our choices on those who cannot speak for themselves.⁶⁴

McCormick posits a different point of view, that, although every person is of "equal value," not every life is of equal value.⁶⁵ In his opinion, it is acceptable to make qualitative judgments about human life and that this in accord with concern for the

⁶⁰ Kelly, K. New Directions in Moral Theology (Geoffrey Chapman, London, 1992) 41.

⁶¹ Ibid., 42.

⁶² Ibid., 42-43; 45-46.

⁶³ Meilaender, G. "Quaestio Disputata. Ordinary and Extraordinary Treatments: When Does Quality of Life Count?" Theological Studies (1997) 58 527-531 at 528.

⁶⁴ Ibid., at 529, 530.

⁶⁵ McCormick, R. How Brave a New World: Dilemmas in Bioethics (SCM Press Ltd., London, 1981) 397.

sanctity of life.⁶⁶ According to him, modern technology has enabled those patients' lives to be saved who in the past would have died due to infection or other problems. In his opinion, the most difficult decisions are made, not on the sanctity of life, but on the quality of life that the patient would have, if he were allowed to live.⁶⁷ He suggests that, where a person is being allowed to die, the process could be hastened by active intervention.⁶⁸

6.2.5 Contributions from A Christian Perspective: Euthanasia and The Intrinsic Wrong of Deliberate Killing

According to Grisez, the human person is the unity of both body and soul, which makes the body an established part of who he 'is' and not something that he 'has.'⁶⁹ Human life is not a tool with which the person pursues his personal ends, it cannot be disposed of at will, because to do so would be to say that we are "non-bodily selves who have and use bodies to pursue our lives."⁷⁰ Therefore, illness or any debility of the body does not affect the sanctity of life.⁷¹ He acknowledges that death can be desired by those who are in pain, or suffering, but not necessarily with an intention to end one's life or be killed and choosing to kill an innocent person is always wrong.⁷² However, sometimes one can knowingly cause death, without actually intending it, when it is a side effect, which one can foresee, but is not caused directly.⁷³ An example would be the hastening of death as a result of pain relieving medication, where the intention is to relieve pain,

⁶⁶ Ibid., 401.

⁶⁷ Ibid., 22.

⁶⁸ Ibid., 23.

⁶⁹ Grisez, G. The Way of The Lord Jesus, Vol. 2, Living A Christian Life (1993) 461, 464.

⁷⁰ Ibid., 465.

⁷¹ Ibid., 466, 477.

⁷² Ibid., 470.

⁷³ Ibid., 471, 475.

not to cause death. Intention to commit suicide or ask others to assist in this involves an intention to kill an innocent person, which always remains a wrong.⁷⁴

Ashley, Deblois and O'Rourke suggest that, for the Christian, human life is a gift from God where the control of that life implies stewardship, not absolute autonomy.⁷⁵ For those who do not believe in God, this may not necessarily be true; however, since life is a basic human good, every means should be taken to preserve that life and the life of others. Their view is that suicide is an act of self-destruction, although some justify it as an autonomous act and assisted suicide as an act of compassion.⁷⁶ They acknowledge that, where the person is incapacitated and is judged to be suffering, in some way, some may consider euthanasia to be a solution to end that suffering, with or without the patient's consent.⁷⁷

May comments that the secularist view of the incapacitated person is related to the person's state of consciousness and the human body is perceived as something outside the consciousness and, therefore, as sub-personal.⁷⁸ Justification for non-voluntary euthanasia is often given that the patient has no quality of life, that it is of no value to him/her and death would be a benefit.⁷⁹ May points out that, by identifying the human person with consciousness, any human that is not yet conscious or never again will be conscious is considered not a person.⁸⁰ Therefore, bodily life is perceived as being only

⁷⁴ Ibid., 477.

⁷⁵ Ashley, B., Deblois, J., O'Rourke, K. Health Care Ethics: A Theological Analysis, 5th ed., (Georgetown University Press, Washington, U.S.A., 2006) 182.

⁷⁶ Ibid., 178, 179, 180.

⁷⁷ Ibid., 183.

⁷⁸ May, W. An Introduction to Moral Theology 2nd ed. (Our Sunday Visitor Inc., Indiana, USA., 2003) 42.

⁷⁹ May, W. Catholic Bioethics and The Gift of Human Life 2nd ed., (Our Sunday Visitor Inc., Indiana, USA., 2008) 266-267; Watt, H. "Euthanasia: Unpacking The Debate" [Online] (2002).

⁸⁰ Ibid., 267-268.

a good when the person is conscious and, when unconscious, the person would be better off dead and euthanasia becomes a reasonable option.⁸¹

Where some treatments may entail a risk to the patient, for example in surgery, Ashley, Deblois and O'Rourke state that there must be a proportionate reason, that is, a proportionate benefit to burden for the patient in undertaking such a risk and the reasons for what is being done and why, must be objectively good.⁸² Grisez also states that risking life as a matter of carrying out such a choice is wrong and gravely so, because it is to give a conditional will to kill, since the choice is of death, if the risk should materialise.⁸³

Pellegrino points out that progress in medicine has made it difficult to differentiate between ordinary and extraordinary means and that the "proper and prudential" use of the concept "futility" can avoid some of the dangers.⁸⁴ When the health-care professional is unable to promote the further good of the patient, any treatment which could harm the patient is avoided and both the finality of human life and, for a Christian, its destiny are accepted.⁸⁵

6.2.6 Concluding Evaluation

Mahoney and Cahill are right to question the boundaries and distinctions of the refusal of treatment which is extraordinary and Pellegrino rightly points out that the terms, 'ordinary' and 'extraordinary' are confusing in the light of contemporary medicine and treatments. However, there are some situations where "proportionate and extra-

⁸¹ Ibid., 267.

⁸² Ashley, B., Deblois, J., O'Rourke, K. Health Care Ethics: A Theological Analysis, 5th ed., (2006) 186-187.

⁸³ Grisez, G. The Way of The Lord Jesus, Vol. 2, Living A Christian Life (1993) 487.

⁸⁴ Pellegrino, E. Decision at The End of Life: The Use and Abuse of The Concept of Futility [Online].

⁸⁵ Ibid.

ordinary” means could be obligatory for the patient and to determine that treatment is ‘futile’ could place the patient at risk of being allowed to die unnecessarily; therefore, there needs to be clarity about what euthanasia is.⁸⁶

Cahill points out, there *is* a distinction between killing and ‘letting die’ and it is not always wrong to ‘intend’ death if this is for the good of the patient. However, this could mean that, based on the incompetent patient’s ‘autonomous right’ to refuse treatment that is burdensome, disproportionate and extraordinary, decisions could be made to withhold antibiotics or to withhold or withdraw nutrition and hydration administered artificially, with the intention of ending his/her life. As part of a broad definition of euthanasia, ‘letting die’ or an ‘omission to act,’ therefore, with the primary intention of causing or hastening death, means, as Mahoney points out, that the most vulnerable are at risk because their lives are considered not to have any value. Furthermore, the patient’s right to withdraw or refuse extraordinary treatment legitimately may not be recognised in a broad definition of euthanasia. For example, some patients who require chemotherapy to prolong life may consider this disproportionate, extraordinary and burdensome and may refuse treatment and, as Kaveny points out, this is not intending death, but is acknowledging the patient’s right to live without being burdened by unwanted medical treatment.⁸⁷ In order to prevent abuse of certain vulnerable people, Cahill suggests limiting euthanasia to being only voluntary, but this is too narrow and would appear to suggest ‘involuntary’ and ‘non-voluntary’ are not forms of euthanasia, which would also place the vulnerable at risk.

⁸⁶ Calipari, M. “The Principle of Ethical Adequacy in The Use of Means of Preserving Life: Between Therapeutic Excess and Abandonment of The Patient.” in Sgreccia, E., Laffitte, J., Alongside The Incurably Sick and Dying Person: Ethical and Practical Aspects (Libreria Editrice Vaticana, Città del Vaticano, 2009) 158-177 at 174.; Evangelium vitae, n.65.

⁸⁷ Kaveny, M. “Assisted Suicide, Euthanasia, and The Law.” Theological Studies (1997) 58: 124-148 at 125.

K. Kelly is right to point out that some people may not wish to live if they perceive their life is not worth living; however, there is a difference between refusing treatment that is burdensome and refusing treatment with the intention to end one's life.⁸⁸ This analysis, therefore, raises some further points. Grisez and May also acknowledge the distinction between the right to refuse burdensome treatment and the relief of suffering, but to withhold or withdraw treatment, or to increase pain-relieving medication or palliative sedation, with the 'intention' of ending the patient's life or hastening his/her death, is directly and deliberately to kill the patient and this is euthanasia. The intention to alleviate suffering is legitimate, but the distinction lies in the willing of an end, that of death or relief from suffering, from, the choice of a means, that of the deliberate choice of an act or an omission in order to cause the patient's death, as distinct from accepting foreseen side effects.⁸⁹ Therefore, any action or omission with the intention of ending the patient's life disregards the dignity of the patient, the sanctity of his/her life and would seem to be euthanasia.

6.3 Withdrawing and Withholding Artificial Nutrition and Hydration

6.3.1 Papal Magisterium

'Jura et bona' does not refer specifically to artificial nutrition and hydration (ANH) as being a medical intervention. The declaration focuses on the benefits and burdens of any medical intervention and whether it is proportionate or disproportionate, taking into account the type of treatment to be used, the patient's physical, mental and moral resources and the degree of risk to him/her, the cost, as well as the outcome of the results.⁹⁰ Although there is no obligation to use all or every "life-maintaining technique" or to make recourse to extraordinary measures in order to save that life, the Pontifical

⁸⁸ Ibid., 42-43; 45-46.

⁸⁹ Grisez, G. The Way of The Lord Jesus, Vol. 2 Living a Christian Life (1993) 470.

⁹⁰ Jura et bona, 515.

Council Cor Unum states that there is still a strict obligation to apply “minimal” therapeutic measures, including ‘alimentation,’ and to interrupt these would be equivalent to ending the patient’s life.⁹¹ For those patients who would appear to be in a permanent irreversible coma, all “care,” that is ordinary care due to every human being, should continue and this includes “feeding.”⁹² Since the patient is unconscious, this would include feeding by artificial means.

John Paul II’s address to the Bishops from California, Nevada and Hawaii, in 1998, confirmed the statement made by the United States (U.S.) Bishops in 1992, that “the omission of nutrition and hydration intended to cause a patient’s death” must be rejected and that the presumption should be in favour of providing medically assisted nutrition and hydration.⁹³ Later, in his allocution of 2004 he states that the administration of ANH is not medical treatment and that this “always represents a natural means of preserving life and is part of normal care.”⁹⁴ Specifically referring to those in a “permanent vegetative state” (PVS), he affirms that the dignity and value of these patients do not change and they have the right to receive nutrition and hydration, an ordinary means of preserving life, even by artificial means.⁹⁵ Life itself is sufficient enough for such support and there is no justification in determining that, after a year of being in a PVS, the patient has no prospects of any quality of life and that ANH can be

⁹¹ Pontifical Council Cor Unum, “Questions of Ethics Regarding The Fatally Ill and The Dying,” Vatican Press, 1981, pp. 8-9, in, O’Rourke, K., Boyle, P. Medical Ethics: Sources of Catholic Teachings, 3rd ed. (1999) 220.

⁹² Pontifical Academy of Sciences, Report on Prolonging Life and Determining Death (30 October 1985), *Health Progress*, Dec. 1985, p.31 in O’Rourke, K., Boyle, P., Medical Ethics: Sources of Catholic Teachings, 3rd. ed. (Georgetown University Press, 1999) 78-79 at 78.

⁹³ John Paul II, Ad Limina Address to Bishops from California, Nevada, and Hawaii. “Building a Culture of Life,” (October 2, 1998), *Origins* 28, no. 18, Oct. 15, 1998, p.316 in O’Rourke, K., Boyle, P. Medical Ethics: Sources of Catholic Teachings, 3rd ed. (1999) 214.

⁹⁴ John Paul II. Address of John Paul II to The Participants in The International Congress on “Life-Sustaining Treatments and Vegetative State: Scientific Advances and Ethical Dilemmas” (20 March 2004) [Online].

⁹⁵ Ibid.

removed.⁹⁶ He states that, if ANH is withdrawn knowingly and willingly, this is euthanasia by omission.⁹⁷

In July, 2005, in response to John Paul II's allocution in 2004, on ANH, the U.S. Bishops sent two follow-up questions to the Congregation for the Doctrine of the Faith asking, "(1) Is the administration of food and water (whether by natural or artificial means) to a patient in a "vegetative state" morally obligatory except when they cannot be assimilated by the patient's body or cannot be administered to the patient without causing significant physical discomfort? (2) When nutrition and hydration are being supplied by artificial means to a patient in a "permanent vegetative state," may they be discontinued when competent physicians judge with moral certainty that the patient will never recover consciousness?"⁹⁸

In August, 2007, the Congregation, answered 'yes' to the first question and 'no' to the second, confirming that it was morally obligatory to administer food and water, including by artificial means, "in principle" to a patient in a "vegetative state."⁹⁹ However, they acknowledged that there will be some situations where it would be impossible to access ANH, for example in a third world country without facilities to provide such a means.¹⁰⁰ As they re-iterated, being in a "persistent vegetative state" is not a terminal illness, the patient is "just not able to feed himself."¹⁰¹ In addition, the provision of ANH is not an excessive burden to any health-care system. If those patients

⁹⁶ Ibid.

⁹⁷ Ibid.

⁹⁸ Peters, E. "Hardt and O'Rourke Err in Minimizing The Scope of The CDF Response." The National Catholic Bioethics Quarterly (2008) 8 (1) 14-15 at 14.

⁹⁹ Congregation for The Doctrine of The Faith. Responses to Certain Questions of The United States Conference of Catholic Bishops Concerning Artificial Nutrition and Hydration [Online] (2007).

¹⁰⁰ Congregation for The Doctrine of The Faith. Commentary: Responses to Certain Questions of The United States Conference of Catholic Bishops Concerning Artificial Nutrition and Hydration [Online] (2007).

¹⁰¹ Ibid.

do not receive such ordinary and proportionate care, their deaths will be due to starvation and dehydration, not of any medical condition.¹⁰²

6.3.2 Bishops from The United States, Ireland and England and Wales

In 1990, the Texas Bishops stated “although life always is a good, there are conditions which, if present, lessen or remove one’s obligation to sustain life” and that the omission of life-sustaining means, including ANH, can be acceptable under some conditions and this is neither murder or suicide nor assisted suicide.¹⁰³ According to them, withholding or withdrawing ANH from a permanently unconscious patient is not abandoning them and each patient should be judged on whether ANH would be a benefit or constitute a burden.¹⁰⁴

The United States National Conference of Catholic Bishops Committee for Pro-Life Activities stated, in 1992, that oral feeding is a form of care owed to all helpless people and affirm that, when medical “treatments” do not involve a burden for the patient but give some hope of benefit, they are considered “ordinary” means and are, therefore, obligatory.¹⁰⁵ They state that not all decisions to withhold or withdraw ANH are attempts to cause the death of the patient and, where the patient faces imminent death and will die whether hydration and nutrition is given or not, since they cannot be assimilated by the body and may be disproportionately burdensome to him, they are not morally obligatory.¹⁰⁶ This does not mean that ANH should be withdrawn with the

¹⁰² Ibid.

¹⁰³ Texas Catholic Bishops and The Texas Conference of Catholic Health Facilities, “On Withdrawing Artificial Nutrition and Hydration,” *Origins* 20: no. 4 (June 7, 1990) 53-55 in Hamel, P., Walters, J., eds., Artificial Nutrition and Hydration and The Permanently Unconscious Patient: The Catholic Debate (Georgetown University Press, Washington, 2007) 109-113 at 110, 111.

¹⁰⁴ Ibid., at 111.

¹⁰⁵ United States National Conference of Catholic Bishops Committee for Pro-Life Activities, Nutrition and Hydration: Moral and Pastoral Reflections, *Origins* 21 no. 44 (9 April 1992), pp. 705-712 in O’Rourke, K., Boyle, P. Medical Ethics: Sources of Catholic Teachings, 3rd ed. (1999) 215-219, at 216.

¹⁰⁶ Ibid., at 216.

intention to cause the patient's death, since a deliberate omission of such, even where it is considered an act of mercy, is an act of euthanasia.¹⁰⁷

According to them, there is a danger that some health-care professionals may withdraw ANH in order to provide a pain-free death; not because the patient is dying, but because the patient is not dying quickly enough, is deemed to have no quality of life or is viewed as being a burden to others.¹⁰⁸ In their opinion, it is a dangerous precedent to imply that a human life is not a positive good and if the burden that one is trying to remove is the burden of being alive in a permanent coma, then this is not morally acceptable.¹⁰⁹

In 1994 the United States National Conference of Catholic Bishops re-affirmed the Church's teaching that, there should be a presumption in favour of providing ANH to all patients, if there is sufficient benefit to outweigh the burdens involved to the patient.¹¹⁰ However, some confusion may have arisen from the Bishops of Illinois's pastoral letter on April 15, 2001, which asserts that every case differs for those requiring ANH and that family members, physicians and staff should feel free to consult with Church ethicists and advisors "in reaching a decision that best serves their patient and loved one."¹¹¹ This, however, is not the position of the Catholic Bishops of England and Wales, who emphasise that all patients should be provided with food and fluids,

¹⁰⁷ Ibid., at 216.

¹⁰⁸ Ibid., at 216.

¹⁰⁹ Ibid., at 218.

¹¹⁰ United States National Conference of Catholic Bishops, "Ethical and Religious Directives for Catholic Health Care Services," *Origins* 24: no. 27 (Dec. 15, 1994) pp. 450-462 in O'Rourke, K., Boyle, P. Medical Ethics: Sources of Catholic Teachings, 3rd., ed. (Georgetown University Press, Washington, 1999) 128-147 at 143: 58.

¹¹¹ Bishops of Illinois, "Facing the End of Life: A Pastoral Letter from The Bishops of Illinois, April 15, 2001" [Online].

considered basic care and it is not morally acceptable to withdraw tube-feeding or other life-sustaining treatment in order to end the patient's life.¹¹²

6.3.3 Contribution from a Christian Perspective: Avoiding too Rigid a Position

In the 1950's, the Jesuit theologian Gerald Kelly referred to the common distinction between ordinary and extraordinary means of treatment, considering "ordinary" such means as can be obtained and used without great difficulty and "extraordinary" those involving excessive difficulty by reason of "physical pain, repugnance, expense and so forth."¹¹³ His view was that, if there was "reasonable hope of success" for recovery, all means should be used, but if the means are used to prolong life by oxygen or "intravenous feeding" where there is no realistic hope of recovery, then there is no automatic requirement to use extraordinary means.¹¹⁴

Mahoney, however, explores the distinction between 'ordinary' and 'extraordinary' means of preserving and sustaining life, maintaining that the terms refer not to the types of treatment, but to the effects of the treatment on the different individuals and the burden to the patient.¹¹⁵ His view is that, to ensure 'quality of life' for the dying person, the treatment that is most appropriate should be chosen and any with distressing side-effects or posing a severe financial burden or incurring severe risks is extraordinary, because it does not support an improvement in the quality of the person's dying.¹¹⁶

¹¹² Catholic Bishops' Conference of England and Wales. "Cherishing Life: Suicide and Euthanasia" [Online] (2004) nn. 180-194 at 185.

¹¹³ Kelly, G. "The Duty of Using Artificial Means of Preserving Life" *Theological Studies* (1950) 11: 203-220 at 204.

¹¹⁴ *Ibid.*, at 203, 213-214, 215.

¹¹⁵ Mahoney, J. *Death and Dying* (1984) 44.

¹¹⁶ *Ibid.*, at 44.

He judges ANH not to be medical ‘treatment’ because to discontinue such is actively to contribute to the person’s death rather than allowing nature to take its course.¹¹⁷ However, he considers that discontinuing the provision of ANH for those in PVS, is not an infringement of their right to life, since they no longer possess that right.¹¹⁸ This is because they no longer have any moral obligations due to their unconsciousness and others are, therefore, not morally obligated to help them.¹¹⁹

Gómez-Lobo notes that, although it is necessary to make a diagnosis, e.g. PVS, in order to treat the patient successfully, this is different from a quality of life judgment, which if poor, is sometimes rationalised to justify euthanasia?¹²⁰ Contrary to Mahoney, he asserts that ANH is medical treatment, since the insertion of a feeding tube, the prescription of appropriate foods and liquids, the monitoring of any side-effects, is all undertaken by the skills of a physician.¹²¹ Similar to Mahoney, he judges that the withdrawal of ANH, may not constitute euthanasia in all situations and may be legitimate, where it is a burden and disproportionate to the outcome.¹²² However, this should not be interpreted as not valuing the patient nor does it necessarily mean that the patient’s death is intended.¹²³

Meilaender takes a different position, claiming that a patient in PVS probably does not experience feeding as burdensome and, since he is not dying and may live for years if fed, it is difficult to claim that feeding him is useless. In his opinion, if ANH that is

¹¹⁷ Ibid., at 46.

¹¹⁸ Mahoney, J. “On a Human Right to Die,” in, Hoose, B., Clague, J., Mannion, G., eds., Moral Theology for The twenty-First Century (T & T Clark Theology, London, 2008) 106-112 at 110, 111.

¹¹⁹ Ibid., at 111.

¹²⁰ Gómez-Lobo, A. “Quality of Life and Assisted Nutrition” in Tollefsen, C., ed., Artificial Nutrition and Hydration: The New Catholic Debate (Springer, The Netherlands, 2008) 103-110 at 103-104, 105.

¹²¹ Ibid., at 106.

¹²² Ibid., at 108.

¹²³ Ibid., at 108.

neither useless nor burdensome is withdrawn, it is not the treatment that is being rejected, but the life and by not nourishing the patient, we are deciding that they should die.¹²⁴

From a different perspective, Hamel and Panicolla argue that, if ANH is considered as basic care and obligatory, then oxygen which also sustains life delivered artificially by mechanical ventilator, should also be considered as obligatory.¹²⁵ However, Gómez-Lobo asserts that the removal of a respirator is not the cause of the patient's death, since patients often continue to live when this happens; it is the prior acute pathological condition which causes death.¹²⁶ Shannon and Walter suggest that what may be 'medically' ordinary or routine, may not be 'morally' ordinary because there may be a disproportion of the benefit-burden ratio for the patient.¹²⁷ According to them, just because an intervention 'is' customarily used, does not necessarily mean that it 'ought' to be morally obligatory because it may not benefit the patient at several levels: it may be a burden, both physically and socially, or it may be contrary to the patient's autonomous wishes and/or to his religious beliefs.¹²⁸

Cahill identifies two viewpoints which she believes are consistent with Catholic tradition, the first, that there is a strong presumption in feeding incompetent patients comprising of three related positions, that withdrawal of ANH is never justified, or that

¹²⁴ Meilaender, G. "Ordinary and Extraordinary Treatments: When Does Quality of Life Count?" *Theological Studies* (1997) 58: 527-531 at 529-530.

¹²⁵ Hamel, R., Panicolla, M. "Must We Preserve Life?" in Hamel, P., Walters, J., eds., *Artificial Nutrition and Hydration and The Permanently Unconscious Patient: The Catholic Debate* (Georgetown University Press, Washington, 2007) 79-88 at 83.

¹²⁶ Gómez-Lobo, A. "Quality of Life and Assisted Nutrition" in Tollefsen, C., ed., *Artificial Nutrition and Hydration: The New Catholic Debate* (2008) 103-110 at 108.

¹²⁷ Shannon, T., Walter, J. "Assisted Nutrition and Hydration and The Catholic Tradition." *Theological Studies* (2005) 66: 651-662 at 657.

¹²⁸ *Ibid.*, 658; Shannon, T., Walter, J. "The PVS Patient and The Forgoing/Withdrawing of Medical Nutrition and Hydration" in Hamel, P., Walters, J., eds., *Artificial Nutrition and Hydration and The Permanently Unconscious Patient: The Catholic Debate* (Georgetown University Press, Washington, 2007) 143-170 at 163.

at times it can be justified if considered burdensome, or even that it cannot be a burden to an unconscious patient and, the second, if quality of life is poor, then ANH is not justified and therefore not morally required.¹²⁹ Her view is that quality of life judgments may be defensible if they respect the needs of the patient and meet objective criteria.¹³⁰

K. Kelly also argues that the withdrawal of ANH, as in the case of Tony Bland, is not incompatible with the Roman Catholic tradition of medical ethics and, from an ethical point of view, should not be regarded as killing him.¹³¹ He views the Catholic medical ethics tradition as always having had a “pro-person” emphasis and to move from this to a depersonalised “pro-life” position where the human good of being alive is regarded as a “quasi-absolute” value is to move away from that tradition.¹³² In his opinion, this would persuade people to support the call for legalised euthanasia, through lack of an acceptable alternative, such as was available in the case of Tony Bland.¹³³

Degnan takes a different position and defends John Paul II’s teaching that the human community is morally obliged to support the patient in PVS with ANH, considered ordinary and proportionate care.¹³⁴ He argues although this does not treat or cure a patient, it should be accorded to every living being and has a reasonable hope of benefit.¹³⁵ Failure to provide such care, especially food and water, is to fail to will the good for the individual within the community and prevent his continued life as a human

¹²⁹ Cahill, L., “Bioethical Decisions to End Life,” *Theological Studies* (1991) 52 107-127 at 110-111.

¹³⁰ *Ibid.* at 114-115.

¹³¹ Kelly, K., “Rest for Tony Bland,” *The Tablet* (1993) 13 March: 247: 332-335 at 334.

¹³² *Ibid.*, at 334.

¹³³ Kelly, K., “Letter re Tony Bland Case,” *The Tablet* (1992) 5 December.

¹³⁴ Degnan, M. “Are We Morally Obligated to Feed PVS Patients Till Natural Death?” in Tollefsen, C., ed., *Artificial Nutrition and Hydration: The New Catholic Debate* (Springer, The Netherlands, 2008) 39-60 at 40.

¹³⁵ *Ibid.*, at 46.

being; this in turn damages the community where each member should be assured of support during any dependent condition.¹³⁵

6.3.4 Contributions from a Christian Perspective: The Dignity of Innocent Human Life

In 1986, a group of moral theologians, moral philosophers, lawyers, medical doctors and nurses, with experience of caring for those in PVS, was convened to study the issues involved in providing food and hydration to the permanently unconscious and other vulnerable persons and to discuss the questions, “Is it ever morally right to withhold or withdraw such nutrition and hydration? If so, on what grounds? And what should be the role of law?”¹³⁶ May, who led the group, claims that the group learned that those in PVS are not suffering from a fatal pathology and can live relative long lives provided they receive nutrition and hydration; at the beginning they are capable of swallowing but it is more convenient to tube-feed them; the cost of feeding them is reasonable and they can be cared for at home.¹³⁷ This position is also supported by Laing, who suggests that the point of a feeding tube is to ease feeding, usually for the nursing staff and other health professions, since to feed the patient orally would impact on the time available to care for the patient.¹³⁸ Like Degnan, she points out that tube feeding is basic care and that there is no attempt to cure or stabilise the patient.¹³⁹

¹³⁵ Ibid., at 46, 49.

¹³⁶ May, W., Barry, R., Griesse, O., Grisez, G., Johnstone, B., Marzen, T., McHugh, J., Meilander, G., Siegler, M., Smith, W. “Feeding and Hydrating the Permanently Unconscious and Other Vulnerable Persons” in Caplan, A., McCartney, J., Sisti, D., eds. The Case of Terri Schiavo: Ethics at The End of Life. (Prometheus Books, New York, 2006) 180-193.

¹³⁷ May, W. “Caring for Persons in The “Persistent Vegetative State” and Pope John Paul II’s March 20 2004 Address “On Life-Sustaining Treatments and The Vegetative State” in Tollefsen, C., ed., Artificial Nutrition and Hydration: The New Catholic Debate (Springer, The Netherlands, 2008) 61-75 at 62.

¹³⁸ Laing, J. “Food and Fluids: Human Law, Human Rights and Human Interests” in Tollefsen, C., ed., Artificial Nutrition and Hydration: The New Catholic Debate (Springer, The Netherlands, 2008) 77-100 at 80.

¹³⁹ Ibid., at 80.

In acknowledging the threat to the dignity of “innocent human life” May et al. reject the judgment made by others that some lives have no value, that providing ANH is excessively burdensome and to withhold or withdraw them is permissible.¹⁴¹ According to them, it is never morally right deliberately to deny food and water by any means to non-competent individuals in order to bring about their deaths, nor should such killing ever be legalised.¹⁴² In certain situations, for example, where the person is imminently dying and where provision of such may be “excessively” burdensome or useless, it may be justified to forego ANH.¹⁴³ If the person is not dying, but is unable to receive nutrition and hydration orally, they believe this should be administered artificially.¹⁴⁴

O’Rourke presents a different argument. Responding to John Paul II’s 2004 allocation on assisted hydration and nutrition, he asserts that the “moral certitude” that the majority of patients in PVS will not recover means there is no hope of benefit to the patient if ANH is continued.¹⁴⁵ In his opinion, ANH is not medical care insofar that it preserves life, but should be morally evaluated by the criteria of hope of benefit and degree of burden.¹⁴⁶ According to him, significant medical evidence suggests that only the conscious experience pain and those in a PVS are not conscious, therefore, there is no obligation to prolong the life of the patient in PVS, since he is unable to participate intellectually and wilfully in a reciprocal relationship with God.¹⁴⁷

¹⁴¹ May, W., Barry, R., Griesse, O., Grisez, G., Johnstone, B., Marzen, T., McHugh, J., Meilander, G., Siegler, M., Smith, W. “Feeding and Hydrating the Permanently Unconscious and Other Vulnerable Persons” in Caplan, A., McCartney, J., Sisti, D., eds. The Case of Terri Schiavo: Ethics at The End of Life. (2006) 180-193 at 183.

¹⁴² Ibid., at 184.

¹⁴³ Ibid., at 184, 185.

¹⁴⁴ Ibid., at 186.

¹⁴⁵ O’Rourke, K. “Reflections on The Papal Allocation Concerning Care for Persistent Vegetative State Patients” in Hamel, P., Walters, J., eds., Artificial Nutrition and Hydration and The Permanently Unconscious Patient: The Catholic Debate (Georgetown University Press, Washington, 2007) 237-253 at 246..

¹⁴⁶ Ibid., at 246-247.

¹⁴⁷ Ibid., at 248-249; Ashley, B., Deblois, J., O’Rourke, K. Health Care Ethics: A Catholic Theological Analysis, 5th ed. (2006) 196, 197.

Lee is not convinced by O'Rourke's argument and points out that, since the human body is part of a human being (body and soul), bodily life and health is part of the achievement of being a human being in union with God, so biological life is a benefit to him.¹⁴⁸ Lee concludes that it is simply false to say that a human person who is body and soul does not benefit from biological life.¹⁴⁹

Grisez offers a different perspective, that of maintaining human solidarity with all who are permanently unconscious, whatever their specific diagnosis.¹⁵⁰ His view is that feeding a comatose person by tube is 'not' complicated, the procedure is used for others who are not comatose, it is 'not' an expensive procedure when separated from the cost of providing ordinary care in a health-care facility and the person can be cared for at home. Many families have "personalistic" reasons for caring for their loved one whom they would never abandon, affirming the dignity of that person and maintaining a bond of human communion with them.¹⁵¹ This not only benefits the patient, but the family benefit in continuing to being a loving family.¹⁵²

He acknowledges that there are some burdens of feeding the comatose, but these are not burdens for the person who presumably cannot experience any of its negative aspect.¹⁵³ If they do experience these burdens, they are not comatose and also might experience the pain of dying from hunger and thirst.¹⁵⁴ He agrees that there are emotions involved

¹⁴⁸ Lee, P. "The Papal Allocation Concerning Care for PVS Patients: A Reply to Fr. O'Rourke" in Tollefsen, C., ed., Artificial Nutrition and Hydration: The New Catholic Debate (Springer, The Netherlands, 2008) 179-187 at 180-181.

¹⁴⁹ *Ibid.*, at 181.

¹⁵⁰ Grisez, G. "Should Nutrition and Hydration Be Provided to Permanently Unconscious and Other Mentally Disabled Persons?" in Hamel, P., Walters, J., eds., Artificial Nutrition and Hydration and The Permanently Unconscious Patient: The Catholic Debate (Georgetown University Press, Washington, 2007) 171-186 at 171, 185.

¹⁵¹ *Ibid.*, at 174-175.

¹⁵² *Ibid.*, at 181.

¹⁵³ *Ibid.*, at 175.

¹⁵⁴ *Ibid.*, at 176.

in caring for a comatose patient and in some countries financial burdens for families; however, this is not a burden of feeding, but a burden of the person's disability; where the burden is removed by not feeding the person, this will only be so because the comatose person will be eliminated.¹⁵⁵ This, he says, is a choice to kill the person, which is homicide.¹⁵⁶ In recognising the benefits of keeping the comatose patient alive, Grisez rejects what he sees as the dualistic view of others, that human life is only an instrumental good and that, unless there is a degree of cognitive function, the person cannot attain other values and there is little point in keeping him/her alive.¹⁵⁷ The living body is an intrinsic part of who the person is, *not* something to be used for his/her good and being unconscious does not mean that s/he is no longer a person.¹⁵⁸

Finnis also recognises the dignity of the debilitated person, and sees this as implying a duty of solidarity towards him/her.¹⁵⁹ Like Grisez, he regards as dualistic the view that human beings only inhabit their bodies and use them, since the living body which is intrinsic to the person's reality also shares in the dignity of the person.¹⁶⁰ He therefore rejects the opinion that the life of the permanently comatose has no value and that he/she would be better off dead, saying that this viewpoint confuses the emotional sense of 'dignity' with the essential sense of 'human dignity.'¹⁶¹ Although those in PVS are "gravely" damaged for the time being, "persistent" does not mean permanent and there is evidence to suggest that several patients in this condition do recover after many years.¹⁶²

¹⁵⁵ Ibid., at 176-177.

¹⁵⁶ Ibid., at 177.

¹⁵⁷ Ibid., at 178.

¹⁵⁸ Ibid., at 181.

¹⁵⁹ Finnis, J. "Economics, Justice and The Value of Life: Concluding Remarks," in Gormally, L., ed., The Dependent Elderly: Autonomy, Justice and Quality of Care (Cambridge University Press, Cambridge, 1992) 189-198 at 196.

¹⁶⁰ Ibid., at 193-194.

¹⁶¹ Ibid., at 192.

¹⁶² Finnis, J. "Bland: Crossing the Rubicon?" The Law Quarterly Review (1993) 109: 329-337 at 334.

is evidence to suggest that several patients in this condition do recover after many years.¹⁶¹

On the same theme, Fisher supports John Paul II's suggestion of re-establishing a "covenant" between the generations to support the most vulnerable in society, including those who are in a PVS.¹⁶² According to him, this means that ANH should be given to those suffering PVS or like conditions because "they are not dead, not dying, not burdened by assisted feeding" and tube-feeding sustains them as it does anyone else.¹⁶³ The presumption should, therefore, be in favour of tube-feeding, when this is necessary to sustain life.¹⁶⁴

Gormally adopts the same position and, reflecting on the legal process in the Bland case, asserts that to adopt the ethical position that withdrawing nutrition and hydration is not euthanasia because it is an "omission" and, the patient has an 'autonomous' right to refuse treatment because his/her life is judged to be no longer worthwhile, is incompatible with respect for the worth and dignity of every human being which is the fundamental assumption of law in the United Kingdom¹⁶⁵

6.3.5 Concluding Evaluation

The administration of ANH where the patient is irreversibly comatose, is regarded by some as ordinary and proportionate care and by others as medical treatment that is extraordinary and disproportionate. Gerald Kelly, in the 1950's differentiated between

¹⁶¹ Finnis, J. "Bland: Crossing the Rubicon?" *The Law Quarterly Review* (1993) 109: 329-337 at 334.

¹⁶² Fisher, A. "Why do Unresponsive Patients Still Matter?" in Tollefsen, C., ed., *Artificial Nutrition and Hydration: The New Catholic Debate* (Springer, The Netherlands, 2008) 3-37 at 21.

¹⁶³ *Ibid.*, at 21.

¹⁶⁴ *Ibid.*, at 21; Gormally L., "The Living Will: The Ethical Framework of a Recent Report" in Gormally, L., ed., *The Dependent Elderly: Autonomy, Justice and Quality of Care* (Cambridge University Press, Cambridge, 1992) 53-69 at 67.

¹⁶⁵ Gormally, L. "Notes on The Winterton Bill." [Online].

“ordinary” and “extraordinary” by the difficulties this would present for the patient, the organisation and for society who has to bear the financial cost. With the accessibility of life-sustaining technology in contemporary society, this terminology can be confusing, for example, Mahoney regards the distinction between ‘ordinary’ and ‘extraordinary’ means as referring to the effects of the treatment on the different individuals and considers ANH not to be medical treatment.¹⁶⁶ Gómez-Lobo on the other hand considers that ANH is medical treatment.¹⁶⁷ Both agree that the discontinuation of them for those in PVS may not constitute euthanasia in all situations, where it is a burden and disproportionate to the outcome, a view similar to that of Shannon and Walter.¹⁶⁸

If ANH is withdrawn or withheld from the PVS patient, this would entail a quality of life judgment that his/her life is not worth continuing which Cahill defends if this respects the needs of the patient and meets objective criteria.¹⁶⁹ This position is similar to that of O’Rourke who asserts that ANH is not medical care insofar that it preserves life, but should be morally evaluated by the criteria of hope of benefit and degree of burden.¹⁷⁰ Neither Cahill nor O’Rourke identify by which objective criteria or moral evaluation this would be made and since Cahill identifies two viewpoints which she believes are consistent with Catholic tradition, there is no guarantee that the right decision will be made for the patient.¹⁷¹ There is a risk that such an evaluation could be undertaken by those with utilitarian motives who would seek to discontinue the

¹⁶⁶ Mahoney, J. *Death and Dying* (1984) 44.

¹⁶⁷ Gómez-Lobo, A. “Quality of Life and Assisted Nutrition” in Tollefsen, C., ed., *Artificial Nutrition and Hydration: The New Catholic Debate* (2008) 103-110 at 103-104, 105.

¹⁶⁸ Shannon, T., Walter, J. “Assisted Nutrition and Hydration and The Catholic Tradition.” *Theological Studies* (2005) 66: 651-662 at 657.

¹⁶⁹ Cahill, L., “Bioethical Decisions to End Life.” *Theological Studies* (1991) 52 107-127 at 114-115.

¹⁷⁰ O’Rourke, K. “Reflections on The Papal Allocation Concerning Care for Persistent Vegetative State Patients” in Hamel, P., Walters, J., eds., *Artificial Nutrition and Hydration and The Permanently Unconscious Patient: The Catholic Debate* (2007) 246-247.

¹⁷¹ Cahill, L., “Bioethical Decisions to End Life.” *Theological Studies* (1991) 52 107-127 at 110-111.

patient's life, on the basis of cost, or, as K. Kelly states, from an ethical point of view which regards the human good of being alive as not an absolute value.¹⁷²

Meilaender and Fisher, on the other hand, assert that those in PVS are not dying and that by 'not' nourishing the patient, we are deciding that s/he should die.¹⁷³ Since, as May, Laing and Degnan agree, tube feeding is basic care, if the person is unable to receive nutrition and hydration orally, then this should be administered artificially.¹⁷⁴ Furthermore, in support of John Paul II's teaching, Grisez, Finnis, Degnan and Fisher, maintain that as a community we are morally obliged to sustain patients in PVS with ANH, maintaining human solidarity with them and, by not abandoning them, this affirms their dignity.¹⁷⁵ Whilst the patient has a right in law to refuse treatment that is burdensome to him, as John Paul II states, the administration of ANH is not medical treatment and "always represents a natural means of preserving life and is part of normal care."¹⁷⁶

¹⁷² Kelly, K., "Rest for Tony Bland," *The Tablet* (1993) 13 March: 247: 332-335 at 334..

¹⁷³ Meilaender, G. "Ordinary and Extraordinary Treatments: When Does Quality of Life Count?" *Theological Studies* (1997) 58: 527-531 at 529-530; Fisher, A. "Why do Unresponsive Patients Still Matter?" in Tollefsen, C., ed., *Artificial Nutrition and Hydration: The New Catholic Debate* (2008) 3-37 at 21.

¹⁷⁴ May, W. "Caring for Persons in the "Persistent Vegetative State" and Pope John Paul II's March 20 2004 Address "On Life-Sustaining Treatments and the Vegetative State" in Tollefsen, C., ed., *Artificial Nutrition and Hydration: The New Catholic Debate* (2008) 61-75 at 62; Laing, J. "Food and Fluids: Human Law, Human Rights and Human Interests" in Tollefsen, C., ed., *Artificial Nutrition and Hydration: The New Catholic Debate* (2008) 77-100 at 80; Degnan, M. "Are We morally Obligated to Feed PVS Patients Till Natural Death?" in Tollefsen, C., ed., *Artificial Nutrition and Hydration: The New Catholic Debate* (2008) 39-60 at 40.

¹⁷⁵ Grisez, G. "Should Nutrition and Hydration Be Provided to Permanently Unconscious and Other Mentally Disabled Persons?" in Hamel, P., Walters, J., eds., *Artificial Nutrition and Hydration and The Permanently Unconscious Patient: The Catholic Debate* (2007) 171-186 at 174-175; Finnis, J. "Economics, Justice and The Value of Life: Concluding Remarks," in Gormally, L., ed., *The Dependent Elderly: Autonomy, Justice and Quality of Care* (Cambridge University Press, Cambridge, 1992) 189-198 at 196; Degnan, M. "Are We morally Obligated to Feed PVS Patients Till Natural Death?" in Tollefsen, C., ed., *Artificial Nutrition and Hydration: The New Catholic Debate* (2008) 39-60 at 40; Fisher, A. "Why do Unresponsive Patients Still Matter?" in Tollefsen, C., ed., *Artificial Nutrition and Hydration: The New Catholic Debate* (2008) 3-37 at 21

¹⁷⁶ John Paul II. *Address of John Paul II to The Participants in The International Congress on "Life-Sustaining Treatments and Vegetative State: Scientific Advances and Ethical Dilemmas"* (20 March 2004) [Online].

Whilst the terms ‘ordinary-extraordinary’ and ‘proportionate-disproportionate’ appear attractive, they are limited in that they are imprecise and could seem to require a ‘quality of life’ assessment by the patient and/or relative or clinician. ‘Ordinary’ and ‘proportionate’ is morally obligatory for both patient and clinician, ‘extraordinary’ and ‘disproportionate’ optional, the clinician having no duty to use these means, not even at the request of the patient.¹⁷⁷ The terms ‘ordinary’ and ‘extraordinary’ are, therefore, inadequate to determine means of treatment for those patients in a PVS, since these require quality of life judgments which can never be truly objective.¹⁷⁸ It is never morally right deliberately to kill an innocent human being and the omission of nutrition and hydration with the intention to cause a patient’s death is euthanasia.¹⁷⁹ This, as Gormally rightly states, is incompatible with respect for the worth and dignity of every human being which is the fundamental assumption of law in the United Kingdom¹⁸⁰

6.4 Conscientious Objection and the Relationship between Moral Evaluation and the Law.

6.4.1 Civil Law and Our Moral Responsibility

The purpose of civil law is to ensure the common good of all people, by promoting peace, public morality and social justice through recognising the fundamental rights which are intrinsic to the person, the first being the “inviolable right to life of every innocent human being.”¹⁸¹ Law is necessary to live in security, harmony and justice and the structure of the society, therefore, should be based solely on the principles of

¹⁷⁷ Calipari, M. “The Principle of Ethical Adequacy in The use of Means of preserving Life: Between Therapeutic Excess and Abandonment of The Patient.” in Sgreccia, E., Laffitte, J., Alongside The Incurably Sick and Dying Person: Ethical and Practical Aspects (2009) 158-177 at 175-176.

¹⁷⁸ Ibid., at 175-176.

¹⁷⁹ Catholic Bishops’ Conference of England and Wales. “Cherishing Life: Suicide and Euthanasia” [Online] (2004) nn. 180-194 at 185.

¹⁸⁰ Gormally, L. “Notes on The Winterton Bill.” [Online].

¹⁸¹ Ibid., n.71; Dignitatis humanae, n.7.

freedom, justice and responsibility.¹⁸² According to the Catechism of the Catholic Church,

“Freedom is the power, rooted in reason and will, to act or not to act, to do this or that, and so to perform deliberate actions on one’s own responsibility....it attains its perfection when directed toward God...”¹⁸³

Good cannot be achieved for the individual if society itself perpetuates actions that are morally wrong and, in order that the dignity of the person is protected at all times, the elected political community and therefore the public authority must act as a moral force directed towards the common good and in supporting the individual.¹⁸⁴ Some societies are not compatible with supporting the individual, for example, a totalitarian system such as a communist state or a theocratic state are two examples, where all sectors of society, including family and personal life, would be at the direction of the state; or in a utilitarian society which focuses on the greatest good for the greatest number.

It is not enough that a government enacts a law, for if this were so, laws which deny justice to a certain sector of society would have to be obeyed, for example the racist laws of South Africa or the National Socialist laws of Germany in 1935 -1945 which undertook the “systematic annihilation” of certain vulnerable sections of the German population.¹⁸⁵ A proper political authority, must therefore take moral responsibility for its people and this means concerning themselves with “human rights, human life and the institution of the family,” serving God through the common good, which can be done through its laws.¹⁸⁶

¹⁸² *Gaudium et spes* n, 26.

¹⁸³ CCC n. 1731.

¹⁸⁴ *Evangelium vitae*, n. 74

¹⁸⁵ Meusch M. “Hadamard: A German Psychiatric Treatment Center in WWII.” *Biomolecular Engineering* [Online] (2001) 17 (2).

¹⁸⁶ Ibid.

Civil law is a form of human law, which, in accordance with right reason, is law which, as citizens of individual countries, we are obliged in conscience to obey; an example would be health and safety laws. Aquinas states that the human authority which makes human laws is inferior to divine authority and therefore cannot impose its laws on judgment of conscience which is guided by God's commandments.¹⁸⁷ Human laws can either be just or unjust and, if that law is contrary to right reason and is unjust, allowing something which is morally wrong, for example, the killing of an innocent human being, there is no strict obligation morally for the Christian to obey it, because it is not a true law.¹⁸⁸ In a democratic society, one would have a duty to change such a law, for even though the majority may desire it, as Pinckaers point out, their views may be based on various subjective opinions which would not have been examined in the light of established moral principles.¹⁸⁹ A civil law, which does not conform to the moral law, lacks "authentic juridical validity" and has no binding force in 'conscience.'¹⁹⁰ However, if a person takes a positive action to disobey a civil law, the consequence is normally a penal action.

6.4.2 Conscientious Objection

Nurses follow a professional code of conduct and unless this code contradicts right reason, they are obliged in conscience to obey it as they undertake the expected service to the public. In this sense, 'conscience' is not a process of psychological conditioning encompassing feelings about what is right or wrong, because this may be shaped by non-rational factors; 'conscience' is an awareness of the basic principles of morality, the moral truth and, is an act of the intellect formed by reflective reasoned moral

¹⁸⁷ Aquinas, T. Summa Theologiae Vol. 28 Law and Political Theory (Blackfriars, Cambridge, 1966) Ia2æ. 90-97 at 96, 4.

¹⁸⁸ Ibid.

¹⁸⁹ Pinckaers, S. Morality: The Catholic View (St. Augustine's Press, Indiana, 2003) 57.

¹⁹⁰ Evangelium vitae, n. 72.

judgment.¹⁹¹ From a Christian perspective, ‘morality’ is about how we relate to each other and to God and about how we use our freedom.¹⁹² We cannot foresee all the consequences of our actions, but morality is about what we “choose” to do, whether directly or by omission.¹⁹³

Whilst Christian nurses are called to obey legitimate public authorities, they should oppose by democratic means, any unjust human laws.¹⁹⁴ Laws which legitimize the direct killing of innocent people are contrary to the principles of absolute respect for life, contrary to reason, opposed to the common good where society exists to serve the individual and, therefore unjust, because, “it ceases to be a law and becomes instead an act of violence.”¹⁹⁵ There is no obligation in conscience to obey such laws and in fact there is a “clear obligation to oppose them by conscientious objection.”¹⁹⁶ “Causing death” should never be considered a form of medical treatment, even at the patient’s request and, Christian nurses are required to exercise conscientious objection in relation to co-operating in an action which would destroy deliberately the life of a human being.¹⁹⁷ As John Paul II states, society has the right and duty to protect itself from false claims of ‘rights’ in the name of ‘conscience and freedom’ to justify killing another person.¹⁹⁸

¹⁹¹ May, W. An Introduction to Moral Theology, 2nd ed., (Our Sunday Visitor, Indiana, 2003) 57-58.

¹⁹² Murray, D. “Co-operation, Complicity and Conscience: The Background to The Debate” in Watt, H., ed. Co-operation, Complicity and Conscience: Problems in Healthcare, Science, Law and Public Policy [The Linacre Centre, London, 2005] 1-11 at 10. [Bishop Donal Murray, Bishop of Limerick and then Chairman of the Irish Bishops’ Committee for Bioethics].

¹⁹³ Ibid., at 10.

¹⁹⁴ Evangelium vitae, n. 73.

¹⁹⁵ Ibid., n.72.

¹⁹⁶ Ibid., n. 73.

¹⁹⁷ Ibid., n. 89.

¹⁹⁸ Ibid., n. 89.

It is important, therefore, that Catholic nurses seek protection for rights through professional bodies, providing these are in harmony with Catholic doctrine. The Association of Catholic Nurses refers nurse clinicians to the General Medical Council guidelines which advises that clinicians can withdraw from providing care if their religious, moral or other personal beliefs lead them to object to complying with, “a) a patient’s decision to refuse life-prolonging treatment, or b) a decision that providing such treatment is not of overall benefit to a patient who lacks capacity to decide.”¹⁹⁹ However, they emphasise that no clinician can do so, without making alternative arrangements for the patient or colleague.²⁰⁰

The Nursing and Midwifery Council focuses on nurses’ legal responsibilities to patients and their accountability for their decisions, which may include being called upon to justify their ‘objection’ within the law.²⁰¹ According to their professional code of practice, nurses and midwives throughout the United Kingdom do not have the right to refuse to take part in emergency treatment and they would be expected to provide care.²⁰²

¹⁹⁹ General Medical Council. Treatment and Care Towards The End Of Life: Good Practice in Decision Making (General Medical Council, London, 2010) n. 79; Association of Catholic Nurses (England and Wales) [Online] [At national level the Association is a registered stakeholder of the NHS National Institute for Health and Clinical Excellence; at international level the Association represents the nursing profession of the Catholic Church of England and Wales on CICIAMS (Comité International Catholique des Infirmières et Assistants Médico-Sociales or International Catholic Committee of Nurses and Medical-Social (Healthcare) Assistants) where Scotland and Ireland are represented independently by their Catholic Nurses Guilds.].

²⁰⁰ Evangelium vitae, n. 79.

²⁰¹ Nursing and Midwifery Council. “Conscientious Objection.” [Online]. [The Royal College of Nursing of the United Kingdom [Online] also provides guidance for nurses on Conscientious objection where the burden of proof differs in Scotland and, England and Wales.]

²⁰² Ibid.

6.4.3 Co-operation

In healthcare, as Myers points out, the language of ‘choice’ and ‘personal autonomy’ formulates the idea that the state must remain neutral on these basic moral choices.²⁰³ The passing of unjust laws creates difficulties for those who make a moral stand against them and refuse to co-operate in what can be a morally wrong action.²⁰⁴ This is especially so for Christian nurses who work in institutions where much good is done, but where they may be faced with difficult choices to co-operate in an action which they consider morally wrong, but, which is viewed as being the patient’s autonomous choice.²⁰⁵ Cooperation between Catholic and secular institutions in managing healthcare, compounds the problem, especially in countries which do not have a national healthcare service. The United States Conference of Catholic Bishops, in recognising the complexities of such situations and the weaknesses in previous ethical and religious directives, states that even those did not prevent misinterpretations and in practice gave rise to problems in concrete applications of the principles.”²⁰⁶ They affirm that Catholic institutions should avoid entering into any partnership that would involve them in the cooperation of the wrongdoing of other providers.²⁰⁷ To do so would place all Christian healthcare professionals at risk of possibly cooperating in a moral wrong.

²⁰³ Myers, R. “U.S. Law and Conscientious Objection in Healthcare” in Watt, H., ed. Co-operation, Complicity and Conscience: Problems in Healthcare, Science, Law and Public Policy [The Linacre Centre, London, 2005] 296-315 at 296, 298. [Richard Myers, Professor of Law, Ave Maria School of Law, U.S.A.].

²⁰⁴ Evangelium vitae, n. 74.

²⁰⁵ *Ibid.* n.89.

²⁰⁶ United States National Conference of Catholic Bishops, “Ethical and Religious Directives for Catholic Health Care Services,” 4th ed., [Online] (2001) Part Six.

²⁰⁷ *Ibid.*

6.4.3.1 Formal, Material Cooperation and Complicity

A Christian nurse can co-operate in a morally wrong action either formally or materially. "Formal cooperation" means that the nurse agrees with what is done and co-operates with another person's action, which is not morally good, by contributing physically to the action.²⁰⁸ An example would be, to assist the doctor in administering euthanasia by preparing the lethal dose of medication and/or holding the patient whilst the lethal dose is given. In this situation the Christian nurse has willingly and freely chosen to actively collaborate proximately and this is always morally wrong because s/he shares in the intention of the action.²⁰⁹ According to Ashley, Deblois and O'Rourke, formal co-operation may also occur if the person advises, encourages or counsels the person principally responsible for the morally wrong action, even if s/he does not take part physically in the action.²¹⁰ An example would be where the nurse advises, encourages or counsels the patient to commit suicide. Although co-operation is an 'action,' 'omissions' are also actions and as Grisez states one can wrongly co-operate by an omission.²¹¹ An example would be where a patient intends to commit suicide by refraining from eating or drinking and the nurse enables him/her to do so by omitting to provide the life-sustaining nourishment. If the nurse co-operates with the patient's action to hasten death deliberately and takes part in some way, is in agreement with the action and contributes physically to the action, then the nurse is cooperating formally with a moral wrong.²¹²

²⁰⁸ Ashley, B., Deblois, J., O'Rourke, K. Health Care Ethics: A Theological Analysis (2006) 55-56.

²⁰⁹ Ibid., 56.

²¹⁰ Ibid., 55.

²¹¹ Grisez, G. The Way of the Lord Jesus Vol. 3, Difficult Moral Questions (Franciscan Press, Illinois, 1997) 872.

²¹² Ashley, B., Deblois, J., O'Rourke, K. Health Care Ethics: A Theological Analysis, 5th ed., (2006) 55-56.

Whilst formal co-operation is to co-operate in the “bad will” of the other person, material (non-formal) co-operation concurs only in the bad ‘action’ of the other, but does not share the nurse’s (co-operator) intention.²¹³ Merely material co-operation can ‘sometimes’ be legitimate if the co-operator’s action is fundamentally good.²¹⁴ For example, a Christian nurse working on a gynaecology ward and who conscientiously objects to abortion can look after the woman after she has had the abortion in order to ensure her safety and wellbeing, but should not give help beforehand because to do so would be to co-operate in a morally wrong action. Were euthanasia to be legalised, Christian nurses who object conscientiously to euthanasia ought not to prepare the patient prior to its administration, since that would be illicit material cooperation. However, the nurse may give practical support to the relatives after euthanasia has been administered to the patient, in order to ensure their wellbeing.²¹⁵ Whilst this does not involve the person directly in the morally wrong action, there is a further distinction between the proximity and remoteness of the nurse’s actions whilst doing his/her job. The more remote his/her actions to the morally wrong act, the easier it is to justify.²¹⁶ As Grisez states, the “co-operator” is the person involved in the wrongdoing initiated by another, but is not the instigator of the wrongdoing.²¹⁷

In practice, as Gormally suggests, nurses may be ‘complicit’ in a moral wrong rather than co-operate formally or materially.²¹⁸ For example, the nurse might fail to advise the other person, or fail to order him, not to act as he intends against the wrongdoing when

²¹³ Grisez, G. The Way of the Lord Jesus Vol. 3, Difficult Moral Questions (1997) at 873.; Fitzpatrick, F. Ethics in Nursing Practice (The Linacre Centre, London, 1988) 130.

²¹⁴ Ashley, B., DeBlois, J., O’Rourke, K. Health Care Ethics: A Theological Analysis, 5th ed., (2006) 55-56.

²¹⁵ Van de Scheur, A., Van der Arend, A. “The Role of Nurses in Euthanasia: A Dutch Study”. Nursing Ethics (1998) 5 (6) 497-508.

²¹⁶ *Ibid.*, 195.-196.

²¹⁷ Grisez, G. The Way of the Lord Jesus Vol. 3, Difficult Moral Questions (1997) 872.

²¹⁸ Gormally, L. “Why Not Dirty Your Hands” in, Watt, H. ed. Co-operation, Complicity and Conscience: Problems in Healthcare, Science, Law and Public Policy [The Linacre Centre, London, 2005] 12-26 at 12.

s/he could and should do so.²²⁰ Often the motivation is to protect one's position in the organisation or to counteract the threat of career prospects being sabotaged for being a whistleblower.²²¹ This may lead to the nurse justifying his/her reasons for being complicit or cooperating in the wrongdoing, by arguing that the wrongdoing is going to occur whether s/he takes part or not.²²² However, this course of action may lead other nurses or patients to regard these procedures as acceptable; therefore, perpetuating a moral wrong.²²³

6.4.3.2 The Patient's Autonomous Choice

Although Christian nurses must respect the decision-making capacity of the 'autonomous' person, they have an obligation to avoid causing harm and to act in the patient's best interests undertaken on Christ's terms.²²⁴ This means discerning whether their own actions constitute moral or physical harm to the patient or to themselves.²²⁵ The patient's freedom to make a decision is good in itself, but his dignity demands that objective judgment is required and necessary, guided by an informed conscience, to ensure that the right decision is made for the right treatment, for his/her good and that of society. For this reason, the patient's right to autonomy should not be the only criterion for making end-of-life choices, since a choice may be made which is not for his/her true good, such as suicide or euthanasia.²²⁶

²²⁰ Ibid., at 13-14.

²²¹ Ibid., at 14.

²²² Ibid., at 15.

²²³ Fitzpatrick, F. Ethics in Nursing Practice (1988) 130.

²²⁴ Delany, M. "General Medical Practice: The Problem of Cooperation in Evil," in Watt, H. ed. Cooperation, Complicity and Conscience: Problems in Healthcare, Science, Law and Public Policy (The Linacre Centre, London, 2005) 128-138 at 131.

²²⁵ Ibid., at 133.

²²⁶ Ibid., nn, 16, 17.

A choice of suicide, either carried out by omission where the patient refuses to eat or drink or where s/he refuses treatment and/or care with the aim of hastening death, may be an autonomous choice, but the decision may have been influenced by other factors such as pain, depression, the persuasion of relatives, or the perception that future life in itself has no possibility of ever being a benefit.²²⁷ Whilst it is possible for a nurse to treat the patient for pain and depression in the hope of changing his/her mind, this becomes more difficult where the patient is incompetent and an advance directive has been signed refusing all treatment, including artificial hydration and nutrition (ANH), with the intention of hastening death.

However, Boyle offers a different perspective that the patient himself, whilst still competent, and without any suicidal intention, decides that the resources used to care for him/her in the future could be used for some other purpose and issues a directive foregoing all treatment including ANH.²²⁸ His view is that those who act in accordance with such a directive are not co-operating in a murder or a suicidal intention, but are honouring the patient's right to refuse treatment and are accepting his/her generosity.²²⁹

6.4.3.3 The Principle of Double Effect

There may be times, however, when a nurse is faced with an action that s/he is morally obliged to perform and where there are undesirable side effects to that action, for example, the administration of pain-relieving drugs which may have the effect of shortening the patient's life. In this situation, providing certain conditions are met, s/he

²²⁷ Watt, H. "Cooperation Problems in Care of Suicidal Patients" in Watt, H. ed. Co-operation, Complicity and Conscience: Problems in Healthcare, Science, Law and Public Policy (The Linacre Centre, London, 2005) 139-147 at 139.

²²⁸ Boyle, J. "The American Debate About Artificial Nutrition and Hydration" in Gormally, L., ed., The Dependent Elderly (Cambridge University Press, 1992) 28-46 at 43; Boyle, J. "Towards Ethical Guidelines for The use of Artificial Nutrition and Hydration" in Tollefsen, C., ed., Artificial Nutrition and Hydration: The New Catholic Debate (Springer, The Netherlands, 2008) 111-121 at 120.

²²⁹ Ibid.

would be doing right, “that the action itself is morally good or at least indifferent (giving medication to relieve pain meets this criterion); the intention is good (we ought to give medication to relieve pain, but not to relieve pain by deliberately causing death); the good effect (the relief of pain) does not follow from the bad effect (the hastening of death); there is a proportionately grave reason for acting as one does (“we cannot risk hastening death in order to relieve an ordinary headache”).²³⁰ The effect of any moral act does not originate in the “outward deed” but in the “inward motive” of the person performing that act and which should never be contrary to the moral law.²³¹

6.4.3.4 Providing Information

In some situations, Christian nurses may be faced with a moral dilemma when asked to provide information to the patient which could instigate a moral wrong, such as euthanasia. As discussed above, formal co-operation may occur if the nurse “advises, encourages or counsels” the person principally responsible for the morally wrong action, even if s/he does not take part physically in the action.²³² Fitzpatrick suggests that the nurse may provide the information, providing s/he does not encourage the patient or assist the patient in any way, but s/he should also express disapproval of such measures.²³³ In reality, this may not be a practical solution, since nurses would not be in a position, professionally, to express personal disapproval to a patient. Whilst problems of co-operation of this nature should be resolved in the light of the moral

²³⁰ Fitzpatrick, F. Ethics in Nursing Practice (1988) 125; Doerflinger, R., Gomez, C. “Killing the Pain, Not the Patient: Palliative Care vs. Assisted Suicide” [Online] [Richard Doerflinger, Associate Director for Policy Development, Secretariat for Pro-Life Activities, U.S. National Conference of Catholic Bishops; Dr. Gomez, Assistant Professor of Medicine, University of Virginia Health System and Medical Director of its Palliative Care Program, USA.].

²³¹ Ashley, B., DeBlois, J, O’Rourke, K. Health Care Ethics: A Theological Analysis, 5th ed., (2006) 56.

²³² *Ibid.*, 55.

²³³ Fitzpatrick, F. Ethics in Nursing Practice (1988) 262.

principles governing co-operation, Christian nurses may choose to not provide the information.²³³

6.4.3.5 Emotions in Decision-Making

Nurses are faced with significant emotional turmoil in making decisions often as a result of their own moral values but sometimes they are affected by how they 'feel' towards the patient.²³⁴ Moral maturity can bring moral emotions, such as anger at injustice, guilt, fear, compassion, distinguishing them from more primitive 'feelings' based on the psychological rushes of emotion, such as pleasure or pain.²³⁵ However, emotions can be irrational, subjective and in many ways self-deceptive and they may motivate the nurse to act in a way, that may not be for the patient's ultimate good.²³⁶ Emotions can also change, influenced by scientific evidence, change in belief system, aesthetic beliefs and therefore they can lose their meaning and value over a period of time.²³⁷ 'Intuitionism' may point the nurse in the right direction, but it is not an independent moral truth since it is not based on reason.²³⁸ If moral judgments are based on 'intuitionism' or personal insights, any differences of opinions within a group of people cannot be reasoned together in the light of moral principles.²³⁹ Nurses, therefore, not only have the freedom to realise good, but they have the freedom to consent to an emotional identification with something that may be morally wrong.²⁴⁰

²³³ Ibid., 270.

²³⁴ Vacek, E. "The Emotions of Care in Health Care" in Cates, D., Lauritzen, P., eds. Medicine and The Ethics of Care (Georgetown University Press, Washington, 2001) 105-141 at 117. (Edward Collins Vacek, S.J. Professor of Christian Ethics, Weston Jesuit School of Theology, Cambridge, Massachusetts, USA.).

²³⁵ Ibid., at 119.

²³⁶ Ibid., at 130.

²³⁷ Ibid., at 122.

²³⁸ Grisez, G., Shaw, R. Fulfillment in Christ: A Summary of Christian Moral Principles (University of Notre Dame Press, London, 1991) 41.

²³⁹ Ibid. 42.

²⁴⁰ Callaghan, S. "The Psychology of Emotions and the Ethics of Care" in Cates, D., Lauritzen, P., eds. Medicine and The Ethics of Care (Georgetown University Press, Washington, 2001) 141-161 at 152.

6.5 Conclusion

For the following reasons, the Church's position, that it is never morally right deliberately to kill an innocent human being, is more convincing than the position forwarded by those used such as Cahill, who argue that it is not always wrong to intend death if this is for the good of the patient.²⁴²

The position of the Catholic Church is that a doctor is not morally obliged to provide extraordinary means to preserve life.²⁴³ In addition, the patient has the right to refuse extraordinary treatment.²⁴⁴ As 'Evangelium vitae' states, to forego extraordinary or disproportionate means is not the equivalent of suicide or euthanasia.²⁴⁵

The first difficulty lies in the interpretation of the terms 'ordinary' and 'extraordinary' means of treatment which requires that a clinician (doctor or nurse) makes a judgment of the patient's degree of pain and whether the treatment would be burdensome to him. To the clinician, 'ordinary' treatment could mean a treatment that is commonly used and 'extraordinary' that the treatment is rarely used.²⁴⁶ To the patient 'ordinary' treatment may be seen as the effect of the treatment, something that is a benefit to him and poses no burden, whilst 'extraordinary' is of no benefit, is a burden and in some cases may be futile where the patient is dying.²⁴⁷ In some countries, 'extraordinary' treatment could refer to those means that are not available or are a financial burden to the institution or family.

²⁴² Jura et bona, 512; Evangelium vitae, n. 65; Cahill, L., "Bioethical Decisions to End Life." Theological Studies (1991) 52 107-127 at 121.

²⁴³ Pontifical Council Cor Unum, Questions of Ethics Regarding The Fatally Ill and The Dying, Vatican Press, 1981, pp.8-9 in O'Rourke, K., Boyle, P. Medical Ethics: Sources of Catholic Teachings, 3rd ed. (1999) 220.

²⁴⁴ Jura et bona 515-516; Evangelium vitae, n.65.

²⁴⁵ Evangelium vitae, n. 65.

²⁴⁶ Kelly, G. "The Duty of Using Artificial Means of Preserving Life" Theological Studies (1950) 11: 203-220 at 204.

²⁴⁷ Mahoney, J. Death and Dying (1984) 44.

However, the patient, who, is permanently unconscious or in PVS, is dependent on the decisions of others, acting on his/her behalf. These might decide that, since the patient appears to be showing no signs of improvement, it would be in his/her best interests, for nutrition and hydration to be withdrawn with the intention of alleviating his suffering and allowing him to die naturally. However, this decision may be based on the patient's 'autonomous rights' and the view that, artificial nutrition and hydration are forms of medical treatment that maybe withheld or withdrawn where it is not contrary to the patient's best interests (*Airedale NHS Trust v Bland* (1993) HL).²⁴⁸ Whilst the patient has a right in law to refuse treatment that is burdensome to him, as John Paul II states, the administration of ANH is not medical treatment and "always represents a natural means of preserving life and is part of normal care."²⁴⁹

Furthermore, those in PVS are not dying, not brain dead and, contrary to O'Rourke's position, there is evidence to suggest that there can be improvement in some patients in the long term.²⁵⁰ The provision of ANH will allow the patient to live for several years and to remove this treatment is to intend his death by dehydration and starvation.²⁵¹ There is a clear moral distinction between 'allowing' a patient to die when that patient is imminently dying and where nutrition and hydration are excessively burdensome to the

²⁴⁸ Maclean, A. Briefcase on Medical Law (2001) 98.

²⁴⁹ John Paul II. Address of John Paul II to The Participants in The International Congress on "Life-Sustaining Treatments and Vegetative State: Scientific Advances and Ethical Dilemmas" (20 March 2004) [Online].

²⁵⁰ May, W. "Caring for Persons in The "Persistent Vegetative State" and Pope John Paul II's March 20 2004 Address "On Life-Sustaining Treatments and The Vegetative State" in Tollefsen, C., ed., Artificial Nutrition and Hydration: The New Catholic Debate (2008) 61-75 at 62; O'Rourke, K. "Reflections on The Papal Allocation Concerning Care for Persistent Vegetative State Patients" in Harmel, P., Walters, J., eds., Artificial Nutrition and Hydration and The Permanently Unconscious Patient: The Catholic Debate (2007) 237-253 at 246; Schnakers, C., Wanhaudenhuyse, A., Glacino, J., Ventura, M., Boly, M., Majerus, S., Moonen, G., Laureys, S. "Diagnostic Accuracy of The Vegetative and minimally Conscious State: Clinical Consensus versus Standardized Neurobehavioural Assessment." BioMed Central (BMC) Neurology [Online] July 2009. [Coma Science Group, Cyclotron Research Center, University of Liege, Belgium.].

²⁵¹ Congregation for The Doctrine of The Faith. Responses to Certain Questions of The United States Conference of Catholic Bishops Concerning Artificial Nutrition and Hydration [Online] (2007)

patient because the body is no longer able to assimilate them and ‘intending’ the patient to die by the withdrawal of nutrition and hydration which is euthanasia by omission. The alleviation of suffering through the purposeful destruction of an innocent human life is contrary to respect for the dignity of the human being and to Christian moral principles.²⁵²

The removal of life-sustaining treatment should be evaluated in the light of the Christian meaning of life to ensure that it is neither a burden to the patient nor that it is withdrawn with the intention of causing death.²⁵³ In addition, the relief of suffering in the terminally ill patient, by administering high doses of pain-relieving medication or palliative sedation, should never be given with the ‘intention’ of hastening the patient’s death.²⁵⁴ This view-point recognises that bodily or biological life, even when severely impaired due to illness, is not a separate entity to be destroyed, but is part of who the person is, and this protects all patients, especially the most vulnerable, ensuring that his/her dignity and sanctity of life is respected and that society remains in solidarity with him/her to a natural death.

When Christian Catholic nurses make end-of-life decisions, these should be based on sound moral teaching and take into consideration the patient’s medical condition as well as the family’s wishes concerning their loved one. However, nurses are responsible for the decision that they make and for what they deliberately do, even if others act in a

²⁵² May, W., Barry, R., Griesse, O., Grisez, G., Johnstone, B., Marzen, T., McHugh, J., Meilander, G., Sieglar, M., Smith, W. “Feeding and Hydrating the Permanently Unconscious and Other Vulnerable Persons” in Caplan, A., McCartney, J., Sisti, D., eds. The Case of Terri Schiavo: Ethics at The End of Life. (2006) 180-193 at 183-184.

²⁵³ United States National Conference of Catholic Bishops, “Ethical and Religious Directives for Catholic Health Care Services,” *Origins* 24: no. 27 (Dec. 15, 1994), pp. 450-462 in O’Rourke, K., Boyle, P., Medical Ethics: Sources of Catholic Teachings, 3rd. ed. (Georgetown University Press, Washington, 1999) 142.

²⁵⁴ Materstvedt, L., Clark, D., Ellershaw, J., Førde, R., Gravgaard, A., Müller-Busch, H., Porta i Sales, J., Rapin, C. “Euthanasia and Physician-Assisted Suicide: A View From An EAPC Ethics Task Force.” Palliative Medicine (2003) 97-101 at 98.

morally wrong way. If a nurse shares in the intention of the action this is formal cooperation.²⁵⁵ If s/he shares in the act directly and proximately, that might be considered also formal cooperation, but it would certainly be illicit material cooperation. Christian nurses should not, therefore, base their decisions on the patient's right to make an autonomous choice, for that choice may involve an ending of a life and the killing of an innocent human being is unjust and there is no strict obligation morally for the Christian nurse to obey it.²⁵⁶ Christian nurses are required, therefore, to exercise conscientious objection in relation to co-operating in an action or an omission with the intention of destroying deliberately the life of a human being.²⁵⁷ In addition Christian nurses should not base their decisions on their emotional feelings, for these may be unreliable.²⁵⁸

Therefore, the Church's position that it is never morally right deliberately to kill an innocent human being, is a more convincing position, since it acknowledges the dignity and value of every human being and protects the most vulnerable patient from being killed deliberately by an action or an omission.

²⁵⁵ Ashley, B., Deblois, J., O'Rourke, K. Health Care Ethics: A Theological Analysis (2006) 55-56.

²⁵⁶ Ibid.

²⁵⁷ Evangelium vitae, n. 89.

²⁵⁸ Vacek, E. "The Emotions of Care in Health Care" in Cates, D., Lauritzen, P., eds. Medicine and The Ethics of Care (2001) 105-141 at 117.

CHAPTER SEVEN
DISCUSSION AND MORAL EVALUATION
IN THE LIGHT OF CHRISTIAN MORAL PRINCIPLES

7.1 Introduction

As discussed in Chapter One there are many different definitions of euthanasia and the terminology does not always have the same meaning with nurses or other professional groups. This chapter examines the similarities and divergences between the empirical findings and the nursing and moral philosophy and theology literature. The findings are then discussed in the light of Christian moral principles to determine what the legalisation of euthanasia could mean for Catholic nurses.¹

The interview study findings cannot be applied in general to all nurses or to all nurses in care homes, since this is one small study of a small group of eleven nurses in one geographical area in Scotland.² Specific attention was taken to ensure rigour in designing and conducting the qualitative interview-based study and ensuring rigour and validity in recording, analysing and reporting the data. What emerges in this chapter is that the findings from the empirical study is supported by much of the literature and confirms that the experiences of nurses in this study reflect that of other nurses' experiences in the United Kingdom and elsewhere.

¹ Chapter Five of this thesis discusses the research findings in relation to nursing literature.

² Chapter Three of this thesis discusses the issues of rigour in qualitative research in detail.

7.2 Examination of Nursing Literature

7.2.1 Where Euthanasia in Some Forms May Be Acceptable

Where nurses perceive 'suffering' as more morally wrong than hastening death, there is a view that physicians should be allowed legally to practise voluntary euthanasia and assisted suicide. There is a view that the patient's mental suffering, fear of a painful death, fears in general, feelings of being alone or abandoned are possible reasons for the patient requesting euthanasia and, where patients die in pain or with unrelieved suffering, nurses can experience guilt and a sense of failure. Some nurses find it difficult to distinguish between pain and agitation, assuming that dying in itself is painful and they embrace euthanasia as a positive act, perceiving their role as relieving the patient's suffering. The patient's suffering therefore, can become the motivating factor for those nurses who are willing to practise euthanasia and there is a view that they refrain only because it is illegal.

Some nurses, who support patient autonomy, perceiving it as leading to an overall quality of life at the end of life, also accept euthanasia, although when those nurses recognise the palliative alternatives, their views can change. There is also a view that end-of-life 'advanced directives' can be of benefit to the patient.

'Quality of life' issues, related to what some nurses regard as the patient's perception of a loss of dignity and control of one's life, can influence decisions on the provision of artificial nutrition and hydration (ANH). These can be perceived as being a physical and psychological burden to the patient, preventing a dignified death and, therefore, the withholding and withdrawing of such as acceptable. Where surrogates make decisions

some nurses observe that their preferences for end-of-life treatment do not always reflect the patient's wishes.

7.2.2 Where Euthanasia in Some Forms May Not Be Acceptable

Some nurses notice that when the patient's pain, fatigue and depression are treated his/her suffering diminishes. However, there are nurses who are cautious about using strong pain medication, fearing that dose increments can lead to sedation and the patient's premature death. Decision-making can be hindered by the perceptions of all those involved (patient, family, staff) of when it is appropriate to give pain-relief. Palliative sedation can be used to relieve symptoms other than pain, including agitation in the terminally ill, but some nurses may consider this wrongly to be euthanasia. Working in the field of palliative care with constant exposure to suffering can influence nurses to change their views on euthanasia and recognise palliative alternatives as preferable.

Voluntary euthanasia is perceived by some nurses as opening the doors to abuse of the most vulnerable patients. They recognise that fear can be a primary emotion within the dying process and consider that, if euthanasia were legal, the patient could have an added fear of it being imposed without consent. Patient autonomy might not be appropriate for those patients not wishing to know their prognosis and some nurses find it stressful to communicate issues related to dying with their elderly patients. Spiritual care, perceived as being both a community and individual response of 'being present,' enhances nurse-patient contact and some nurses regard their role as being the patient's advocate.

The provision of nutrition and hydration is associated by some nurses and families as being linked to “compassion and nurturing,” a symbol of providing life, and dehydration linked to suffering and abandoning the patient. There is also a view that the provision of ANH are basic nursing care at the end of life, even for those patients with dementia or who are incapacitated.

Nurses’ decision-making can be affected by negative emotions, their own, the patients’ and the relatives’, such as anger, despair, feelings of frustration and often eventual stress and burn-out which can prevent them from providing quality care. Coping mechanisms can be helpful, but often these suppress the reality of the burden of emotional labour which impacts on decision-making. Ultimately nurses want their patients to have a good death.

7.3 Examination of The Empirical Research

7.3.1 Where Euthanasia in Some Forms May Be Acceptable

According to some nurses, dying can be prolonged and unbearable for the patient and such suffering can impact emotionally on them and the relatives. To them, dying with dignity and freedom from pain and suffering means, increasing the medication dose to ensure that the patient is unconscious, even though this could result in hastening death. Sometimes it means not contesting the doctor’s decision to withhold or withdraw the provision of antibiotics where the intention is to hasten the patient’s death.

There is a view that patient autonomy is a positive factor, especially in relation to controlling pain relief medication and the provision of ANH. Since the majority of care homes provides only for the administration of subcutaneous fluids and not intravenous

fluids, the decision is left to the patient to choose either option, or none, even with the possibility of dying prematurely. For the patient with dementia, the relative's preferred treatment is followed which might include withdrawing or withholding ANH. Where the patient has a stroke, or swallowing reflexes are diminished, some nurses regard as futile making provision for any form of hydration or nutrition and withholding them an acceptable form of allowing the patient to die. This decision is generally associated with a view that dependence and being unconscious means no quality of life.

7.3.2 Where Euthanasia in Some Forms May Not Be Acceptable

Some nurses foster a belief system in a higher power, which according to them, forms their conscience of what is right or wrong. These nurses and others also believe that there is a right time to die and that no-one should interfere with that process. Their view is that a patient's wish to die might not necessarily be a request to be assisted to die, but is a symptom of depression or fatigue associated with pain. By exploring the reason for the patient's discouragement and treating the problem, they find that patients' attitudes can change. Some nurses notice that where patients appear to be afraid of dying, especially those with dementia, their fear lessens by reassurance, compassion and understanding. Where a relative makes an indirect or direct request to help the patient die, there is a view that this is not necessarily an invitation to hasten death, but an expression of their suffering and by building a relationship with them and giving them emotional support, they change their minds.

Although nurses generally respect the patient's autonomous rights to make decisions conflict can be a problem between patient, relative, doctor and nurse. Where there is conflict between relatives and nurses, some nurses choose to make end-of-life decisions

without their involvement. Decisions made by doctors, especially with regard to ANH and medication, can be perceived by some nurses as unsatisfactory for the patient. They view their role as advocate, necessary to ensure that the right decisions are made for the patient, as well as ensuring that patient fear is lessened and hope is given to both patient and relative.

Nurses are not always clear when or whether, ANH should be withheld or withdrawn and can feel compromised if the patient gives a directive not to give hydration at the end of life. Patients who are unconscious or have dementia and receive fluids appear, to them, less agitated and more comfortable and where a relative intervenes to ensure subcutaneous fluid is provided, this can result in the patient rallying.

Some nurses make decisions based on 'intuition,' or 'feelings' or by comparing the patient before and during illness, sometimes taking into consideration the quality of life after treatment and 'hoping' that the right decision is being made. Quality of life can mean to some nurses an ability to appreciate life in some way, although incapacity is not necessarily regarded as an obstacle to having a quality of life. Some view the patient's life as having value because s/he is a living being and this is not undermined by age, incapacity or the patient's perception that he is a burden to others.

There is no clear consensus on when pain-relieving medication should be withheld or increased and assessment of pain is based on several factors. Diamorphine can be administered because the patient's apparent 'agitation' can alarm friends. Some nurses are cautious about administering pain-relieving medication, especially since the Shipman enquiry, aware of their accountability in law if the patient dies prematurely.

The relationship between doctor and nurse can be complex, doctors sometimes being considered more knowledgeable than nurses and although inappropriate decisions on medication dose could be challenged by some nurses, they might be adhered to by others. Some nurses experience relatives requesting them to increase pain-relieving medication in order to hasten the patient's death, but this is normally rejected.

Although nurses in general consider that they retain their professionalism throughout the patient's dying process, many of them experience intense emotional feelings related to anger at relatives and doctors and feeling "awful" at making wrong decisions. Sometimes emotions manifest in quiet reflection and grief at the loss of a loved patient, whilst intense emotions are perceived as interfering with clear decision-making. Maintaining a professional stance is viewed as allowing nurses to distance themselves from the emotion and make clear decisions regarding patient care.

7.4 Examination of Moral Philosophy and Theology Literature

7.4.1 Where Euthanasia in Some Forms May Be Acceptable

'Suffering' is perceived by some as a reason to hasten death and there is a view that those requiring sedation due to overwhelming pain and suffering should be administered euthanasia, with or without the patient's consent. 'Letting die' is considered by some as a licit form of euthanasia and emotionally acceptable, compared to killing someone directly by assisted suicide, which can also be viewed as an act of compassion. Suicide, acceptable in some cultures and voluntary euthanasia can be justified as autonomous acts. Limiting euthanasia to being only voluntary is considered by some as being a means to preventing abuse and protecting the vulnerable.

There are those who rationalise that a poor quality of life could justify euthanasia, especially if treatment does not support an improvement in the quality of the person's dying, taking into consideration, cost, risks and side-effects. Justification for non-voluntary euthanasia, by active or passive means, is that it is beneficial to the patient who has no quality of life, especially those in PVS.

7.4.2 Where Euthanasia in Some Forms May Not Be Acceptable

Some consider that death can be desired by those patients who are in pain or suffering, but not necessarily with an intention to end one's life. Pain management, psychosocial and spiritual support can increase the patient's well-being and remove depression, thus diminishing the desire for death. It is legitimate to use painkillers, even at the risk of shortening life, but where death is not sought nor intended this is not euthanasia.

There are those who consider that the patient has a right to forego some medical treatment and is never obliged to use extraordinary means. Patients might have different opinions of what is extraordinary treatment or a burden too great to bear and those who refuse treatment might not be expressing a wish to die, but choosing how to live, even if that life is shorter. There is a view that the right to refuse treatment does not mean the "right to die," but the right to live without being burdened by unwanted treatment, even though this may hasten death. However, "rights" are considered by some as meaningless without corresponding claims or obligations and 'autonomy,' as some see it, can become a selfish autonomy.

There is some concern that a doctor's subjective view of the patient's "quality of life" might not take into account all relevant treatments that could be offered and some

doctors could withdraw ANH because the patient is a burden to others and not dying quickly enough. Judgments made for incapacitated patients, allowing them to die, might not necessarily reflect the patient's choice and decisions made on emotional feelings and intuitionism can be unreliable. Some consider that the community has an obligation to care for the incapacitated patient and is morally obliged to support those in PVS with ANH, considered ordinary and proportionate care.

There is also a view that voluntary euthanasia could open the practice to involuntary euthanasia and possible abuse of the most vulnerable. 'Advance directives' are considered by some to be ineffective safeguards because these are dependent on the patient's past wishes and feelings and who might not have had adequate information at that time. For the Christian, control of one's life implies stewardship, not absolute autonomy and illness or any debility of the body does not affect the sanctity of life. Christian suffering is perceived by some as having a special place in God's saving plan, a sharing in Christ's passion and true compassion leads to sharing another's pain, whilst caring for him with patience and love.

7.5 Summary of Similarities and Divergences Between Nursing Literature, Empirical Research and Moral Philosophy and Theology Literature

The nursing literature (N), moral and theological literature (M) support the empirical research (E) that nurses' decision-making can be underpinned by nurses' emotions, including 'feelings' and 'intuitions,' especially where they perceive that the patient and/or relative is suffering in some way. Conflict places an emotional burden on nurses and can interfere in relationships with patients, relatives and doctors (NEM). Patient autonomy perceived as beneficial to the patient (E) is also taken into consideration, but

patient autonomy is not always appropriate (NM). Advance directives are viewed as being both beneficial (N), but also unreliable (M).

There is a view that there is a right time to die which cannot be determined by others (EM) and spiritual care as alleviating the patient's fear of dying (NEM). Where nurses might accept euthanasia in some forms, the patient's suffering can be a strong motivating factor and, if the quality of life is judged as poor, euthanasia in some form becomes an autonomous right (NEM). Some nurses perceive their role as ensuring that the patient 'dies with dignity,' which to them can mean, freedom from pain and suffering (NEM). Some consider that nurses refrain from practising euthanasia only because it is illegal (N).

Where euthanasia in some forms might not be accepted, all patients, including the incapacitated, are valued as living beings and if pain, fatigue and depression are treated, the patient's suffering and desire to die diminish (NEM). Where relatives make a direct or indirect request to hasten the patient's death, this can be rejected (E) and voluntary euthanasia can be perceived as opening the practice to the abuse of the most vulnerable (NM). Nurses can be cautious about using pain-relief medication, perceiving that this could shorten the patient's life prematurely (NEM) and views on palliative sedation are diverse and can be considered as euthanasia (N).

Some nurses are unsure when or whether artificial nutrition and hydration (ANH) should be withheld or withdrawn (E) often considered as an added physical and psychological burden to the patient, but withdrawal of hydration can be viewed by some as the community abandoning the patient (NEM). The provision of ANH can be linked

to compassion and nurturing and some nurses will act as the patient's advocate if these are denied (NE). Although, according to some nurses, relatives' decisions might not reflect the patient's wishes (NEM), a request by them for ANH to be withdrawn can be viewed as acceptable (EM).

7.6 Some Critical Remarks

Despite the perceptions of some people, the use of analgesia to control pain is not contrary to Christian moral principles and, therefore, to be cautious may be to deprive the patient of pain relieving medication. Opioids in palliative care, such as morphine to relieve severe pain and diamorphine to relieve moderate to severe pain, have different titration rates, but are effective medications and should never be denied to the patient. Diamorphine, especially, is extremely effective where the patient is emaciated because it has a greater solubility and allows effective doses to be injected in smaller volumes.³

These are not to be confused with palliative sedation which is treatment used in many settings at the end of life, such as the management of refractory symptoms or for psychological or existential suffering.⁴ In palliative sedation, the patient is assessed regularly for dose titration and, whilst there could be a potential risk of hastening death through respiratory depression, this might be judged trivial relative to the goal of

³ Royal Pharmaceutical Society of Great Britain. British National Formulary 'No. 59: March 2010' (BMJ Group and Pharmaceutical Press, London, 2010) 256.

⁴ Cherny, N., Radbruch, L., The Board of the European Association for Palliative Care. "European Association for Palliative Care (EAPC) Recommended Framework For the Use of Sedation in Palliative Care." Palliative Medicine [Online] (2009) 23 (7); Jones, D. "Approaching The End" [Online] (2007). [Professor David Jones, Academic Director, St. Mary's College, Twickenham, UK]. [Professor David Jones discusses the concept of 'existential suffering' and the practical realities of grief, fear and hope in the face of death.]

eliminating suffering.⁵ Furthermore, continuous deep sedation is usually only ever considered in the very terminal stages of the patient's illness.⁶

If palliative sedation is properly used and is carefully titrated to effect, the benefits to the patient are relief from the burden of suffering; however if it is not used properly, the risk of sedation compromises physiological function and premature death could be the outcome.⁷

There is no objection to the withdrawal of artificial nutrition and hydration in some situations, for example where the body can no longer assimilate either or where death is imminent and tubes could be painful and/or burdensome or cause distress to the patient due to common problems such as, aspiration pneumonia, ulceration surrounding the entrance area of the tube and blockage and infections.⁸ The withdrawal of hydration at the end of life is not abandoning the patient where it is no longer a benefit to him.

Advance directives are not necessarily wrong. They might prevent a patient from being given unwanted 'aggressive treatment' such as imposing radical chemotherapy which would be disproportionate to the expected results and impose a burden on the patient.⁹

⁵ Cherny, N., Radbruch, L., The Board of the European Association for Palliative Care. "European Association for Palliative Care (EAPC) Recommended Framework For the Use of Sedation in Palliative Care." Palliative Medicine [Online] (2009) 23 (7); Some examples of palliative sedation are: Midazolam, a short-acting benzodiazepine, barbiturates such as Phenobarbital, neuroleptics such as Chlorpromazine or general anaesthetics which have a high titration rate such as Propofol. [Titration – a method of estimating the amount of solute in a solution. The solution is added in small, measured quantities to a known volume of a standard solution until a reaction occurs.]

⁶ Ibid.

⁷ Cherny, N., Radbruch, L., The Board of the European Association for Palliative Care. "European Association for Palliative Care (EAPC) Recommended Framework For the Use of Sedation in Palliative Care." Palliative Medicine [Online] (2009) 23 (7).

⁸ Sheehan, M. "Feeding Tubes: Sorting Out The Issues" in Hamel, R., Walter, J., eds., Artificial Nutrition and Hydration and The Permanently Unconscious Patient: The Catholic Debate (Georgetown University Press, Washington, 2007) 15-25 at 18-19.

⁹ Evangelium vitae, n. 65.

They are especially useful where the patient has no close relatives or where s/he might lack capacity to make decisions in the future.

Bodily life is not an absolute, for, if it were, there would be no room for defending oneself against an aggressor or for criminals being executed in extreme circumstances or for martyrdom. It is right that the patient dies with dignity and that he is free from pain and suffering and it is right that the autonomous rights of the patient are respected. There is no obligation to have extraordinary treatment and this must always be based on several factors; for example, the patient's general state of health, the cost of the treatment, the distance from the place where the treatment is to take place and separation from family and friends.

It is right that the relatives' wishes are respected and they are involved in the decision-making, since not only are they emotionally involved, they can also be left with the burden of caring for that patient. There are financial burdens in some countries and practicalities in general, as well as the emotional burden which may be overwhelming for some families and which may impact on their health.

These are sensitive areas where not everyone is in agreement; nevertheless, if euthanasia were legalised, how would nurses be affected? Some nurses may welcome euthanasia, feeling easier in their conscience that the patient would not be suffering. Furthermore, if they collaborated, they would be less likely to be disciplined or risk promotion being denied them. However, those nurses who are sensitive to Catholic moral doctrine might have difficulties and a number of problems could arise.

7.7 What the Legalisation of Euthanasia could mean for Catholic Nurses¹⁰

The Catholic moral principles underpinning a Catholic Nurse's personal and professional life mean that s/he ought to choose never to cooperate in the direct and deliberate killing of an innocent life. Christian nurses might be pressurised to cooperate with this action, but have the freedom to choose to do something which is morally right or wrong. Christian nurses work as part of a team and, if euthanasia were legal, the decisions that are made within the team could impact significantly on their personal well-being and their professional life in the following ways.

It is possible that the relief of suffering in the terminally ill patient could be achieved by administering high doses of pain-relieving medication or palliative sedation with the intention of ending the patient's life. Whilst it is permissible to use painkillers and sedatives, even at the risk of shortening life, the alleviation of suffering through the purposeful destruction of an innocent human life is contrary to respect for the dignity of the human being and to Christian moral principles.¹¹ If the Christian nurse willingly and freely chooses to actively collaborate proximately with euthanasia, s/he is sharing in the intention of the action and this is always morally wrong. However, if s/he collaborates with the act proximately, but does not share in the intention of the act, this could be illicit material co-operation and, whilst this might not impact on the nurse professionally, it could possibly have a negative psychological and spiritual impact. By choosing not to co-operate to end the patient's life, the nurse could face disciplinary action, unless there is provision to object conscientiously.

¹⁰ The legislation that was proposed in England in Lord Joffe's "Assisted Dying for The Terminally Ill Bill" (2006) and Lord Falconer of Thoroton's "Coroners and Justice Bill: Amendment 173" (2009) and in Scotland, Margaret MacDonald, MSP's, "The Proposed End-of-Life Choices (Scotland) Bill: Consultation Document (2008), involves a definition which is narrow in comparison with what is envisaged in this section.

¹¹ *Evangelium vitae*, n. 65.

The withdrawal and withholding of ANH could be perceived as a legitimate means to end the patient's life. To remove ANH is to intend the patient's death by dehydration and starvation and even where it is considered an act of mercy, is euthanasia by omission. Christian nurses have a strict obligation to provide hydration and nutrition, including by artificial means, considered as ordinary care.¹² They should evaluate the decision to withdraw or withhold ANH in light of the Christian meaning of life, to ensure that it is neither a burden to the patient nor that it is withheld or withdrawn with the intention of causing death. The decision not to cooperate with this action could cause conflict within the team and could mean disciplinary action against the nurse. However, to co-operate with this action is to co-operate in the deliberate ending of an innocent life and this is always morally wrong. Ultimately this could have a negative psychological and spiritual impact on the nurse.

The patient's right to refuse aggressive medical care should not be confused with deliberately refusing ordinary treatment in order to shorten one's life.¹³ Even where the patient makes an autonomous decision for euthanasia or an advance directive specifies the deliberate intention to hasten a patient's death, this is morally wrong and Christian nurses ought not to cooperate with a decision or directive with this intention. However, the consequence of refusing to cooperate with a legal directive could incur a penal or professional action against the nurse.

A relative's decision could involve a morally wrong intention to end the patient's life and a Christian nurse, wishing to avoid conflict might co-operate and end up doing something that is morally wrong. Christian nurses are responsible for the decisions that

¹² Ibid.

¹³ Grisez, G. The Way of The Lord Jesus Vol. 3 Difficult Moral Questions (1997) 205.

they make and for what they deliberately do, even if others act in a morally wrong way. No matter how difficult the circumstances, Christian nurses have a duty to ensure that the patient is not deliberately killed.¹⁴ Where voluntary euthanasia is perceived as a solution to ending suffering, the patient's decision may not have been free of controlling interferences from others or made with adequate understanding of the issues involved. Furthermore, involuntary and non-voluntary euthanasia might not reflect the patient's wishes, known to the nurse. Therefore, the Christian nurse's role as advocate could include a new responsibility, that of protecting the patient from euthanasia.

The patient or his relative could request information on assisted suicide and euthanasia. If a Christian nurse advises, encourages or counsels such acts the person who will be principally responsible for the morally wrong action, even if s/he does not take part physically in the action, this is formal co-operation in a morally wrong action. If the Christian nurse chooses not to provide the patient with such information, this could mean a breach of the 'Nurses' Code of Professional Conduct' and his/her duty to act as an 'advocate' by helping patients access relevant information.¹⁵ This could have professional implications for Christian nurses.

The Christian nurse could find that s/he is required by the institution to cooperate in euthanasia as part of a formal employee contractual agreement. The motivation to protect one's career could lead the nurse to justify agreeing to cooperate with such an arrangement. To do so would be to perpetuate a moral wrong. Christian nurses are required to exercise conscientious objection in relation to co-operating with euthanasia.

¹⁴ Grisez, G., Shaw, R. Fulfillment in Christ: A Summary of Christian Moral Principles (1991) 121-122.

¹⁵ Nursing and Midwifery Council. "The Code" [Online] (2008).

However, this could potentially lead to the employer severing the employment contract and resulting professional, family and social consequences for the nurse.

Where a decision is made to administer euthanasia to a patient, the Christian nurse could be required, as part of the team to co-operate in preparing the patient for euthanasia. If the Christian nurse chooses to do so, this could be illicit material co-operation in a moral wrong. If the nurse chooses to object conscientiously to euthanasia s/he ought not to prepare the patient prior to the administration of euthanasia; however, this could have implications for human resources within the team and impact negatively on relationships with colleagues.

Nurses should normally obey the law of the land, as should anyone else, but not if it requires them to do what is morally wrong. If they do not follow what appears to be required of them, were euthanasia to be legalised, they could face penal and/or professional action. Catholic nurses should follow guidance about how to exercise conscientious objection to avoid conflicts with the law.

7.8 Conclusion

As discussed in this chapter, many of the arguments for euthanasia are concerned with quality of life and respect for autonomy. There are different meanings and understandings of the sanctity of life and the dignity of the individual which can impact on decisions relating to the withdrawal or withholding of artificial nutrition and hydration as well as the administration of pain-relieving medication.

According to some nurses, patients and their relatives perceive suffering as pointless and euthanasia can be viewed as a compassionate solution to end suffering where the patient is in pain, overwhelmed with grief and where all hope appears to be gone. Nurses can be burdened by their own emotions as well as those of the patient and family and these could impact on decision-making. Whilst they should always act with compassion, Christian nurses ought never to make a decision to do anything that is morally wrong.

If euthanasia were legal, Christian nurses would be faced with the choice of doing something for the good or bad. Their choice could impact on their own psychological and spiritual well-being, their relationships with colleagues, their legal and professional accountability, their professional career or employment prospects, affecting their family and social well-being and could change their role as advocate to prevent the deliberate and direct killing of an innocent life.

CHAPTER EIGHT

CONCLUSION AND RECOMMENDATIONS

8.1 Introduction

The aim of the research was to explore the meaning of euthanasia and nurses' experiences of how decisions are made on end-of-life care in private care homes and to discuss how the legalisation of euthanasia could impact on the Christian nurse's role in caring for the patient, in the light of Christian Moral Principles.

This chapter will focus on: a) the limitations in conducting the whole thesis, b) the results of the enquiry, c) recommendations in the context of national developments which seek to improve the quality of care at the end-of-life in care homes and other settings.

8.2 Limitations in Conducting The Thesis as A Whole

8.2.1 The researcher encountered obstacles when integrating nursing, moral philosophical and theological aspects with the empirical research, which she had not envisaged when first commencing the research. Each subject is extensive and the difficulty lay in reducing the subject matter, whilst ensuring that rich information important to the research was retained.

8.2.2 The use of terminology does not always have the same meaning for nurses, Catholic theologians, philosophers, legal bodies and medical professionals. This created difficulties when reading relevant material and endeavouring to discern their appropriateness to the research study.

8.2.3 Referencing in nursing and theological traditions differs. A coherent, reference style encompassing both traditions has been adopted.

8.2.4 The original plan for a quantitative research study had to be abandoned after approval was refused. For a qualitative research study, eleven nurses volunteered to participate in the research study and, for practical reasons, these were recruited from one geographical area. This, therefore, is a very small study and the findings cannot be generalised to the wider body of nurses or nurses working in care homes. If the study were repeated in other parts of the United Kingdom, where there is a greater diversity of cultures, different results may be obtained.

8.2.5 'Euthanasia' was not discussed with the participants for ethical reasons. Discussion of the subject could have illuminated other aspects of nurses' attitudes to euthanasia and could have enriched the study.

8.3 Results of Adopting a Christian/Catholic Approach

Adopting a Christian/Catholic approach has enabled the researcher to analyse critically the moral foundations and the decision-making process for Christian nurses. Thus, the researcher would want Christian nurses to think about the following key points when considering the whole question of end-of-life issues as discussed in chapter seven: the sanctity of life; the dignity and value of life; suffering as redemptive; autonomy; advance directives; the use of medication; hydration and nutrition; and what is meant by 'best interests.'

8.4 New Contribution to Knowledge

- The study has contributed new information on the basis of experiences of one group of nurses working in care homes and how they make end-of-life decisions.
- The study confirms research already undertaken on end-of-life decision-making and the experiences of other nurses in the United Kingdom, as well as other countries.
- This study is new in its explicit attempt to examine these findings in the light of Catholic moral principles.
- This study is new in its explicit attempt to apply Catholic moral principles to such empirical findings.
- This study is new in its attempt to elicit indications of the possible impact of any legalisation of euthanasia upon nurses, especially Catholic nurses, and their practice.

The study found that the majority of nurses interviewed judged that there is a right time to die and no-one should interfere with that process. A minority of nurses consider that it is acceptable, in certain circumstances, to allow, the withholding of artificial nutrition and hydration in order to allow the patient to die. Legalising euthanasia could mean that the Christian nurse's role as advocate could change and include a new responsibility, that of protecting the patient from euthanasia.

The nursing literature supports the empirical findings that where nurses would accept euthanasia in some forms, suffering is a motivating factor; where nurses would not

accept euthanasia in any form this is due to their religious/spiritual beliefs; that pain-relieving medication should be administered properly to the patient, but not with the intention of ending life; that artificial nutrition and hydration should neither be a burden to the patient nor should be withdrawn with the intention of ending life.

The moral analysis conducted in this study concludes that no-one has the right directly and deliberately to kill another human being and that euthanasia is a false mercy; that life-sustaining treatment should neither be a burden to the patient nor be withdrawn with the intention of causing death; that properly used pain-relieving medication and palliative sedation are appropriate at the end of life; and that hydration and nutrition, even artificial, ought to be provided as ordinary care.

My understanding of these principles has been challenged but deepened in studying them and in comparing them honestly with contrary opinions; that no innocent human being should be deliberately and directly killed; pain relieving medication should be used, even at the risk of shortening the life of the dying patient; nutrition and hydration should always be provided to sustain the life of the patient and there are some procedures that may be considered a burden to the dying patient that may be discontinued, but not with the intention to kill.

8. 5 Recommendations

The following recommendations are offered in the context of current initiatives, namely the Government's White Paper, 'Equity and Excellence: Liberating the NHS' (2010), the Scottish Government's 'Living Living and Dying Well: Short Life Working Group 7 Final Report' (March 2010)" and 'National End-of-Life Care Programme Supporting

People to Live and Die Well: A Framework for Social Care at the End-of-life' [July 2010].¹

These do seek to, a) introduce a national choice for all end-of-life care patients to support their preferences about how to have a good death, b) address palliative and end-of-life care from a public health and health promotion perspective across society, c) ensure necessary training and education in assessment for all health care professionals and social workers.

The following recommendations are deliberately directed towards Catholic nurses, but also to include other Christian health-care workers and social workers.

That Christian nurses are enabled:

1. To develop a Christian understanding of the sanctity of life; earthly life is not an absolute value.
2. To know and understand the proper distinction between ordinary and extraordinary means.
3. To increase their knowledge on the proper administration of analgesia so that nurses are not over-cautious in its use and these meet the needs of the patient.

¹ Department of Health. "Equity and Excellence: Liberating the NHS." [Her Majesty's Stationary Office, UK, 2010]; The Scottish Government. "Living and Dying Well: Short Life Working Group 7 Final Report" [Online] (March 2010); NHS National End of Life Care Programme. "Supporting People to Live and Die Well: A Framework for Social Care at the End-of-life" [Online] [July 2010].

4. To explore an understanding of the Christian meaning of suffering and death to help patients, families and carers interpret their experiences in the light of the Gospel.
5. To apply Christian moral principles to the care of the human being who is weak and suffering, whatever his religion.
6. To accompany the sick and dying person with compassion, but without doing what is morally wrong.

8.6 Recommendations For Future Research Studies

- 1) A larger qualitative study incorporating several geographical areas in the United Kingdom should be undertaken to explore further nurses' experiences on decision-making on end-of-life issues in care homes.
- 2) A quantitative survey of nurses should be undertaken in the United Kingdom, so that individual nurses are consulted on their views opinions on and attitudes towards the practice of euthanasia.

BIBLIOGRAPHY

Part I

1. Church Documents

Catechism of The Catholic Church, Revised ed., (Burns & Oates, London, 1999).

1.1 Papal Documents

Pius XII, The Attempt on Innocent Human Life (26 November 1951), *The Human Body: Papal Teachings*, p. 182 in O'Rourke, K., Boyle, P. Medical Ethics: Sources of Catholic Teachings, 3rd. ed., (Georgetown University Press, Washington, 1999).

Vatican II, Dignitatis Humanae (7 December 1965), in Flannery, A., ed., Vatican Council II, Vol. 1, Revised ed., (Costello Publishing Company, New York, 1996).

Vatican II, Gaudium et Spes (7 December 1965) in Flannery, A., ed., Vatican Council II, Vol. 1 Revised ed. (Costello Publishing Company, New York, 1996).

John Paul II, Ad Limina Address to Bishops From California, Nevada, and Hawaii. "Building a Culture of Life," (October 2, 1998), Origins 28, no. 18, Oct. 15, 1998, p.316 in O'Rourke, K., Boyle, P. Medical Ethics: Sources of Catholic Teachings, 3rd ed. (1999).

John Paul II. Address of John Paul II to The Participants in The International Congress on "Life-Sustaining Treatments and Vegetative State: Scientific Advances and Ethical Dilemmas" (20 March 2004) [Online]. Available from: http://www.vatican.va/holy_father/john_paul_ii/speeches/2004/march/documents/hf_jp-ii... [Accessed 1 October 2007].

John Paul II. Evangelium vitae (Catholic Truth Society, London, 1995).

John Paul II. Veritatis splendor (The Catholic Truth Society, London, 1993).

1.2 Documents of Vatican Congregations and Councils.

Congregation for The Doctrine of The Faith. Responses to Certain Questions of The United States Conference of Catholic Bishops Concerning Artificial Nutrition and Hydration [Online] (2007). Available from: http://www.vatican.va/roman_curia/congregations/cfaith/documents/rc_con_cfaith_doc_2 [Accessed 19 September 2007].

Congregation for The Doctrine of The Faith. Commentary: Responses to Certain Questions of The United States Conference of Catholic Bishops Concerning Artificial Nutrition and Hydration [Online] (2007). Available from: http://www.vatican.va/roman_curia/congregations/cfaith/documents/rc_con_cfaith_doc_2... [Accessed 19 September 2007].

Pontifical Council Cor Unum, Questions of Ethics Regarding The Fatally Ill and The Dying, Vatican Press, 1981, in, O'Rourke, K., Boyle, P., Medical Ethics: Sources of Catholic Teachings, 3rd. ed. (Georgetown University Press, Washington, 1999).

Pontifical Academy of Sciences, Report on Prolonging Life and Determining Death (30 October 1985), Health Progress, Dec. 1985, p.31 in O'Rourke, K., Boyle, P., Medical Ethics: Sources of Catholic Teachings, 3rd. ed. (Georgetown University Press, 1999).

Sacred Congregation for The Doctrine of The Faith. Jura et bona (5 May 1980), in Flannery, A., ed., Vatican Council II, Vol. 2., More Post Conciliar Documents, Revised ed., (Costello Publishing Company, New York, 1998).

1.3 Episcopal Conference Documents

Catholic Bishops' Conference of England and Wales. "A Practical Guide to The Spiritual Care of The Dying Person: Ethical Issues in Care Towards The End of Life" [Online] (2010) Available from: <http://www.catholic-ew.org.uk/content/download/7340/50436/file/guide-to-spiritual-care-of-dying.pdf> [Accessed 9 July 2010].

Catholic Bishops' Conference of England and Wales. "Cherishing Life". [Online] (2004). Available from: http://www.catholic-ew.org.uk/content/download/956/9550/file/Cherishing_Life_2004.pdf. [Accessed 28 February 2010].

Catholic Bishop's Conference of England and Wales. "Choosing the Common Good" (2010) [Online]. Available from: <http://www.catholic-ew.org.uk/content/download/6490/44766file/20pp.pdf> [Accessed 10 July 2010].

Catholic Bishops' Conference of England and Wales. "Interim Policy for Prosecutors in Respect of Cases of Assisted Suicide issued by The Director of Public Prosecutions (DPP): Response from The Catholic Bishop's Conference of England and Wales" (Catholic Trust for England and Wales, London, 2009).

Catholic Bishops Conference of Scotland. "Euthanasia" [Online] 27 August, 2008. Available from: <http://scmo.org/articles/11/1Euthanasia/Page1.html> [Accessed 23 December 2009].

The Linacre Centre for Health Care Ethics, "Response to The Draft Mental Incapacity Bill: A Joint Submission by The Catholic Bishops' Conference of England and Wales and The Linacre Centre for Healthcare Ethics." (September, 2003) [Online]. Available from: <http://www.linacre.org/JointSubmissionLatest.html> [Accessed 5 June, 2010].

United States Catholic Conference Advisory Committee on Ethical and Religious Directives for Catholic Health Facilities, "Guidelines for The Determination of Brain Death", Hospital Progress, Dec. 1975, p.26 in O'Rourke, K., Boyle, P., Medical Ethics: Sources of Catholic Teachings, 3rd. ed. (Georgetown University Press, 1999).

United States National Conference of Catholic Bishops Committee for Pro-Life Activities, "Guidelines for Legislation on Life-Sustaining Treatment" (10 November 1984), Origins 14: no. 32, Jan. 24, 1985, pp. 526-528 in O'Rourke, K., Boyle, P., Medical Ethics: Source of Catholic Teachings, 3rd ed, (Georgetown University Press, Washington, 1999).

United States National Conference of Catholic Bishops Committee for Pro-Life Activities, "Statement on Uniform Rights of The Terminally Ill Act" (20 March 1986), Origins 16: no. 12, Sept. 4, 1986, pp. 222-224 in O'Rourke, K., Boyle, P., Medical Ethics: Sources of Catholic Teachings, 3rd. ed. (Georgetown University Press, Washington, 1999).

United States National Conference of Catholic Bishops Committee for Pro-Life Activities, "Nutrition and Hydration: Moral and Pastoral Reflections", Origins 21 no. 44 (9 April 1992), pp. 705-712 in O'Rourke, K., Boyle, P. Medical Ethics: Sources of Catholic Teachings, 3rd ed. (Georgetown University Press, Washington, 1999).

United States National Conference of Catholic Bishops, "Ethical and Religious Directives for Catholic Health Care Services", Origins 24: no. 27 (15 December 1994), pp.450-462, in O'Rourke, K., Boyle, P. Medical Ethics: Sources of Catholic Teachings, 3rd. ed.. (Georgetown University Press, Washington, 1999).

United States National Conference of Catholic Bishops, "Ethical and Religious Directives for Catholic Health Care Services," 4th ed. [Online] (2001). Available from: <http://www.nccbuscc.org/bishops/directives.shtml> [Accessed 10 June 2010].

1.4 Other Documents for American Bishops

Bishops of Illinois, "Facing the End of Life: A Pastoral Letter from The Bishops of Illinois, April 15, 2001" [Online]. Available from: http://www.lifeissues.net/writers/bis/bis_01facingendoflife.html [Accessed 6 June 2010].

Michigan Bishops, "Living and Dying According to The Voice of Faith," Origins 27: no. 19 (Oct., 23, 1997), pp. 318-321 in O'Rourke, K., Boyle, P. Medical Ethics: Sources of Catholic Teachings, 3rd ed. (Georgetown University Press, Washington, 1999).

New Mexico Bishops, "An Opportune Time to Review The Correctional System", Origins 26: no. 36 (27 February 1997), pp. 586-588 in O'Rourke, K., Boyle, P., Medical Ethics: Sources of Catholic Teachings, 3rd. ed. (Georgetown University Press, Washington, 1999).

Texas Catholic Bishops and The Texas Conference of Catholic Health Facilities, "On Withdrawing Artificial Nutrition and Hydration," Origins 20: no. 4 (June 7, 1990) 53-55 in Hamel, P., Walters, J., eds., Artificial Nutrition and Hydration and The Permanently Unconscious Patient: The Catholic Debate (Georgetown University Press, Washington, 2007)

1.5 Bioethics Committees

Catholic Bishops' Joint Bioethics Committee [Online] (2010). Available from: <http://www.catholic-bioethics.org.uk/> [Accessed 10 January, 2010].

Irish Bishops' Committee for Bioethics. "End-of-Life Care: Ethical and Pastoral Issues" [Online] (2002).

Available from: <http://www.healthcare-ethics.ie/endoflifecare.htm> [Accessed 12 January, 2010].

Irish Catholic Bishops Consultative Group for Bioethics [Online] (2009). Available from: <http://www.healthcare-ethics.ie/home.html> [Accessed 10 January, 2010].

Scottish Council on Human Bioethics [Online]. Available from: <http://www.schb.org.uk/> [Accessed 2 September, 2009].

Scottish Council on Human Bioethics. "Press Release: Director of Public Prosecutions – Assisted Suicide Proposals." [Online] (2009) 23 September. Available from: <http://www.schb.org.uk/publications/press%2048%20-%20assisted%20suicide%20pr...> [Accessed 31 October, 2009].

Scottish Council on Human Bioethics. "Press Release: Ms. Debbie Purdy Assisted Dying Proposals" [Online] (2009) 30 July.

Available from: <http://www.schb.org.uk/publications/press%2047%20-%20debbie%20purdie.htm> [Accessed 2 September, 2009].

Scottish Council on Human Bioethics. "Position Statement: Assisted Suicide" [Online] (March 2010). Available from:

<http://www.schb.org.uk/publications/position%2002%20-%20assisted%20suicide.htm> [Accessed 28 July, 2010].

Scottish Council on Human Bioethics. "Position Statement: Euthanasia" [Online] (March 2010). Available from:

<http://www.schb.org.uk/publications/position%2003%20-%20euthanasia.htm> [Accessed 28 July, 2010].

The Linacre Centre for Health Care Ethics, "Submission to The Select Committee of The House of Lords on Medical Ethics" (1993) in Gormally, L., ed. Euthanasia, Clinical Practice and The Law (The Linacre Centre, London, England, 1994).

2. United Kingdom Official Sources and Documents

Association of Catholic Nurses England and Wales [Online] Available from: <http://www.catholicnurses.org.uk/> [Accessed 9 July, 2010].

British Medical Association. "Assisted Dying – A Summary of The BMA's Position" [Online] (2009) 20 February. Available from: http://www.bma.org.uk/ethics/end_life_issues/Assisdyingsum.jsp [Accessed 2 September, 2009].

British Medical Association. "End-Of-Life Decisions" [Online] (August 2009). Available from: <http://www.bma.org.uk> [Accessed 2 August, 2010].

Catholic Communications Network. "Comment by Archbishop Peter Smith on Assisted Suicide Amendments to the Coroners and Justice Bill" [Online] (19 May, 2009). Available from: http://www.catholic-ew.org.uk/ccb/layout/set/print/catholic_church/media_centre/pres... [Accessed 14 December, 2009].

Crown Court: Family Division. "Judgment: Airedale NHS Trust-v-Bland Family Division [1992] 2 WLR 316 (19 November 1992)." Lawindexpro – Case Law [Online]. Available from: http://www.swarb.co.uk/c/fd/1992airedale_bland.html [Accessed 5 February, 2004].

Department of Health. Care Homes for Older People: National Minimum Standards (Her Majesty's Stationery Office, London, 2002).

Department of Health. "Equity and Excellence: Liberating the NHS." [Online] (2010). Available from: http://www.dh.gov.uk/en/Publicationsandstatistics/Publications/PublicationsPolicyAndGuidance/DH_117353 [Accessed 25 July, 2010].

Her Majesty's Stationary Office (H.M.S.O.) "Data Protection Act 1998" [Online] Available from: <http://www.hmsso.gov.uk/acts/acts1998/19980029.htm> [Accessed 25 January, 2003].

House of Lords (HL) Bill 36. "Assisted Dying for The Terminally Ill Bill" [Online] (2005). Available from: <http://www.publications.parliament.uk/pa/ld200506/ldbills/036/06036.i.html> [Accessed 14 June, 2006].

Lord Falconer of Thoroton, "Coroners And Justice Bill: Amendment 173" in, "Lord Hansard Text For 7 Jul 2009." [Online]. Available from: <http://www.publications.parliament.uk/pa/ld200809/ldhansrd/text90707-0006.htm> [Accessed 1 September, 2009].

MacDonald, M. "The Proposed End Of Life Choices (Scotland) Bill: Consultation Document 2008" [Online] Available from: <http://www.scottish.parliament.uk/s3/bills/MembersBills/pdfs/EndOfLifeChoicesConsultation.pdf> [Accessed 1 September, 2009].

National End of Life Care Programme. "Supporting People to Live and Die Well: A Framework for Social Care at the End-of-life" [Online] [July 2010]. Available from: <http://www.endoflifecareforadults.nhs.uk/publications/supporting-people-to-live-and-die-well-a-framework> [Accessed 25 July, 2010].

"NHS Central Office for Research Ethics Committees (COREC)." [Online] Available at: <http://www.corec.org.uk>. [1 November, 2002].

Nursing and Midwifery Council. "Conscientious Objection." [Online] Available from: <http://www.nmc-uk.org/Nurses-and-midwives/Advice-by-topic/A/A...> [Accessed 10 July, 2010].

Nursing and Midwifery Council. "Guidelines for Prosecutors on Assisted Suicide" [Online] (24 September 2009). Available from; <http://www.nmc-uk.org/Press-and-media/News-archive/Guidelines-f...> [Accessed 3 August, 2010].

Nursing and Midwifery Council (NMC). "NMC Response to RCN Decision on Assisted Suicide" [Online] (2009). Available from: <http://www.nmc-uk.org/aArticle.aspx?ArticleID=3814> [Accessed 12 September, 2009].

Nursing and Midwifery Council for Nurses and Midwives. "Standards for Medicines Management" [Online]. Available from: www.nmc-uk.org. [Accessed 6 June, 2006]

Nursing and Midwifery Council. "The Code: Standards of Conduct, Performance and Ethics for Nurses and Midwives" [Online] (2008). Available from: www.nmc-uk.org. [Accessed 14 June, 2009].

Office for National Statistics. "Religious Populations: Christianity is Main Religion in Britain" [Online] (2004). Available from: <http://www.statistics.gov.uk/cci/nugget.asp?id=954> [Accessed 31 May, 2010].

Report of Lord Cameron of Lochbroom to The Inner House of The Court Of Session in The Cause Law Hospital NHS Trust (Pursuers) against Lord Advocate and Others (Defenders) (Court of Session Edinburgh, 1996).

Royal College of Nursing. "Assisted Suicide Consultation" [Online] (2009). Available from: <http://www.rcn.org.uk> [Accessed 3 June, 2009].

Royal College of Nursing. "Conscientious Objection." [Online]. Available from: <http://www.rcn.org.uk/search?q=conscientius+objection> [Accessed 10 July, 2010].

The Crown Prosecution Service. "Policy for Prosecutors in Respect of Cases of Encouraging or Assisting Suicide." [Online] (2010). Available from: http://www.cops.gov.uk/publications/prosecution/assisted_suicide_po... [Accessed 9 June, 2010].

The High Court of Justice: Family Division. "Approved Judgment: Ms. B and An NHS Hospital Trust [2002] EWHC 429 (Fam)" The Court Service – Family Division – Judgment [Online]. Available from: <http://www.courtservice.gov.uk/judgmentsfiles/j1075/BvNHS.htm> [Accessed 27 February, 2004].

The Scottish Government. "Living and Dying Well: Short Life Working Group 7: Final Report" [Online] (March 2010). Available from: www.scotland.gov.uk/Resource/Doc/924/0081652.doc [Accessed 25 July, 2010].

The Shipman Inquiry (2001) [Online] Available from: <http://www.the-shipman-inquiry.org.uk/home.asp> [Accessed 18 August, 2007].

3. International Official Documents

Comparative Constitutions. "Dignity, Death and the Depth of Comparative Engagement in the US," ComparativeConstitutions.org [Online]. Available from: <http://www.comparativeconstituitions.org/2009/09/dignity-death-depth-of-comparative.html> [Accessed 21 October, 2009].

Comité International Catholique des Infirmières et Assistants Médico-Sociales (CICIAMS) [Online] Available from: <http://www.ciciams.org/executivecommittee.html> [Accessed 9 July, 2010].

Family Research Council. "Legal Brief – In the Supreme Court of The State of Montana: Case DA09-0051" Family Research Council [Online]. Available from: <http://www.frc.org/legalbrief/amicus-brief--baxter-v-montana> [Accessed 21 October, 2009].

International Council of Nurses. "International Code of Ethics for Nurses" [Online] (2006). Available from: <http://www.icn.ch/> [Accessed 2 June, 2008].

Legislative Assembly of The Northern Territory. "The Rights of The terminally Ill (ROTI) Act, 1995" [Online]. Available from: <http://www.nt.gov.au/lant/parliament/committees/rotti/parldebate.shtml> [Accessed 5 October, 2009].

Ministry of Health, Welfare and Sport and The Ministry of Justice. "Euthanasia The Netherland's New Rules: The Termination of Life on Request and Assisted Suicide (Review Procedures) Act" (2002) [Online]. Available from: http://www.academiavita.org/english/AltriDocumenti/org_int/OLA... [Accessed 3 September, 2009].

Paperchase Newsburst. "Swiss Court Extends Physician-Assisted Suicide to Incurable Mental Patients." Jurist: Legal News and Research [Online] (2007). Available from: <http://jurist.law.pitt.edu/paperchase/2007/02/swiss-court-extends-physician-assisted.php> [Accessed 17 October, 2009].

Portail Santé, Grand-Duché de Luxembourg. Guide des Soins Palliatifs [Online]. Available from : <http://www.sante.public.lu/fr/actualities/2009/06/guide-soins-palliatif...> [Accessed 4 October, 2010]

State Law Library of Montana. "Montana Supreme Court Cases: Baxter v. State (DA 09-0051)" [Online] (2009). Available from: http://fnweb1.isd.doa.state.mt.us/idmws/custom/JUDCOMMON/SLL_FN_banner.htm [Accessed 7 January, 2010].

State of Oregon. "State of Oregon Death with Dignity Act - Legislative Statute [Online] (2004)." Available from: <http://www.oregon.gov/DHS/ph/pas/ors.shtml> [Accessed 9 September, 2009].

Washington State Department of Health. "Washington State Death with Dignity Act, Initiative 1000" [Online] (2008). Available from: <http://www.doh.wa.gov/dwda/> [Accessed 9 September, 2009].

Part II

1. Books

Ashley, B., Debois, J., O'Rourke, K. Health Care Ethics: A Theological Analysis, 5th ed., (Georgetown University Press, Washington, U.S.A., 2006).

Aquinas, T. Summa Theologiae Vol. 28 Law and Political Theory (Blackfriars, Cambridge, 1966).

Beauchamp, T., Childress, J. Principles of Biomedical Ethics, 6th ed., (Oxford University Press, New York, Oxford, 2009).

Burns, N., Groves, S. The Practice of Nursing Research: Conduct, Critique and Utilization, 5th ed., (Elsevier Saunders, Missouri, USA, 2005).

Cessario, R. Introduction to Moral Theology (The Catholic University of America Press, Washington, 2001).

Cohen, L., Manion, L., Morrison, K. Research Methods in Education, 5th ed., (Routledge Falmer, London, 2000).

Creswell, J. Research Design: Qualitative, Quantitative and Mixed Methods Approaches, 3rd. ed., (Sage Publications Inc. California, USA, 2009).

- Curran, C.E. Moral Theology: A Continuing Journey (University of Notre Dame Press, Notre Dame-London, 1982).
- Edwards, S. Nursing Ethics: A Principle-Based Approach, 2nd ed. (Palgrave Macmillan, Basingstoke, 2009).
- Engelhardt, H.T. The Foundations of Bioethics (Oxford University Press, Inc. New York, 1986).
- Fitzpatrick, F. Ethics in Nursing Practice (The Linacre Centre, London, 1988).
- Gormally, L., ed. Euthanasia, Clinical Practice and The Law (The Linacre Centre, London, England, 1994).
- Grisez, G. The Way of The Lord Jesus, Vol. 1, Christian Moral Principles (Franciscan Herald Press, Chicago, 1983).
- Grisez, G. The Way of The Lord Jesus, Vol. 2, Living A Christian Life (Franciscan Press, Illinois, 1993).
- Grisez, G. The Way of The Lord Jesus Vol. 3 Difficult Moral Questions (Franciscan Press, Illinois, 1997).
- Grisez, G., Shaw, R. Fulfillment in Christ: A Summary of Christian Moral Principles (University of Notre Dame Press, Notre Dame, 1991).
- Harris, J. The Value of Life: An Introduction to Medical Ethics (Routledge & Kegan Paul, 1985).
- Jones, D. Approaching The End [Online Book] (2007). Available from: <http://www.oxfordscholarship.com/oso/public/content/religion/9780...> [Accessed 2 June, 2010].
- Kelly, K. New Directions in Moral Theology (Geoffrey Chapman, London, 1992).
- MacLean, A. Briefcase on Medical Law (Cavendish Publishing Ltd., London, 2001).
- Macnee, C., McCabe, S. Understanding Nursing Research: Reading and Using Research In Evidence-Based Practice, 2nd. ed., (Walters Kluwer/Lippincott Williams & Wilkins, Philadelphia, 2008)
- Mahoney, J. Bioethics and Belief (Christian Classics, Inc., Maryland, USA, 1984).
- Mahoney, J. Death and Dying (Sheed & Ward Ltd., London, England, 1984).
- May, W. An Introduction to Moral Theology 2nd. ed. (Our Sunday Visitor Inc., Indiana, USA, 2003).
- May, W. Catholic Bioethics and The Gift of Human Life 2nd ed., (Our Sunday Visitor Inc., Indiana, USA, 2008).

McCormick, R. How Brave A New World?: Dilemmas in Bioethics (SCM Press Ltd., London, 1981).

O'Collins, G., Farrugia, E., A Concise Dictionary of Theology, Revised ed., (T & T Clark, Edinburgh, 2000)

Parahoo, K. Nursing Research: Principles, Process and Issues (Palgrave, Basingstoke, 1997).

Pinckaers, S. Morality: The Catholic View (St. Augustine's Press, Indiana, 2003).

Polit, D., Beck, C. Nursing Research: Principles and Methods, 7th ed., (Lippincott Williams & Wilkins, 2004).

Punch, K. Introduction to Social Research: Quantitative and Qualitative Approaches, 2nd. ed. (Sage Publications Ltd., London, 2005).

Royal College of Nursing. Research Ethics (The Royal College of Nursing of The United Kingdom, London, 1998).

Royal Pharmaceutical Society of Great Britain. British National Formulary 'No. 59: March 2010' (BMJ Group and Pharmaceutical Press, London, 2010).

Singer, P. Practical Ethics, 2nd ed., (Cambridge University Press, Cambridge, 1993).

Streubert, H., Carpenter, D. Qualitative Research in Nursing: Advancing the Humanistic Imperative, 2nd ed., (Lippincott, Philadelphia, 1999).

Watt, H. Life and Death in Healthcare Ethics (Routledge, Taylor & Francis Group, London, 2000).

Weller, B., ed., Baillière's Nurses' Dictionary for Nurses and Health Care Workers, 25th ed., (Baillière Tindall Elsevier Ltd., Edinburgh, 2009).

Woodall, G. Special Moral Theology: A Course Book for The BA Divinity Programme [Unpublished] (Maryvale Institute, Birmingham, 2000).

Woodall, G. Fundamental Moral Theology: A Course Book for The BA Divinity Programme [Unpublished] (Maryvale Institute, Birmingham, 2001).

2. Articles

Andolsen, B. "Care and Justice as Moral Values for Nurses in an Era of Managed Care" in, Cates, D., Lauritzen, P., eds. Medicine and the Ethics of Care (Georgetown University Press, Washington, 2001).

Asai, A., Ohnishi, M., Nagata, S., Tanida, N., Yamazaki, Y. "Doctors' and Nurses' Attitudes Towards and Experiences of Voluntary Euthanasia: Survey of Members of The Japanese Association of Palliative Medicine." Journal of Medical Ethics (2001) 27.

Asch, David A. "The Role of Critical Care Nurses in Euthanasia and Assisted Suicide." The New England Journal of Medicine [Online] (1996) 334 (21). Available from: <http://gateway.uk.ovid.com/gw2/ovidweb.cgi> [Accessed 11 February 2001].

Back, A., Young, J., McCown, E., Engelberg, R., Vig, E., Reinke, L., Wenrich, M., McGrath, B., Curtis, J. "Abandonment at The End Of life From Patient, Caregiver, Nurse and Physician Perspectives." Archives Internal Medicine (2009) 169 (5) 474-479.

Barbour, R. "Checklists for Improving Rigour in Qualitative Research: A Case of the Tail Wagging the Dog?" British Medical Journal [Online] (2001), 322. Available from: <http://www.bmj.com/cgi/content/full/322/7294/1115> [Accessed 17 June 2009].

Begley, C. "Using Triangulation in Nursing Research." Journal of Advanced Nursing [Online] (1996) 24 (1). Available from: <http://biomed.niss.ac.uk/ovidweb/ovidweb.cgi> [Accessed 7 November 2002].

Benton, D., Cormack, D., "Gaining Access to The Research Site" in Cormack, D., ed., The Research Process in Nursing, 4th ed. (Blackwell Sciences Ltd., London, 2000).

Berghs, M., Dierckx de Casterlé, B., Gastmans, C. "The Complexity of Nurses' Attitudes Toward Euthanasia: A Review of The Literature." Journal of Medical Ethics (2005).

Berterv, C. "Editorial: Fatigue The most common Problem Within People Afflicted with Cancer; Challenge for Health Care Professionals – Widening Our Perspectives on Existential Issues." Austral-Asian Journal of Cancer [Online] (2009) (8) 4. Available from: <http://www.ajcancer.ipp-sht.cqu.edu.au/issus/editorial.php?issueid-41> [Accessed 26 January 2010].

Beširević, V. "End-Of-Life Care in The 21st Century: Advance Directives in Universal Rights Discourse." Bioethics (2010) 24 (3) 105-112.

Bloomer, M., Tiruvoipati, R., Tsiripillis, M., Botha, J. "End-Of-Life Management of Adult Patients in an Australian Metropolitan Intensive Care Unit: A Retrospective Observational Study." Australian Critical Care (2010) 23: 13-19.

Boyle, J. "Field Research: A Collaborative Model for Practice and Research" in Morse, J., ed., Qualitative Nursing Research, 2nd ed., (Sage Publications Inc., Newbury Park, 1991).

Boyle, J. "The American Debate About Artificial Nutrition and Hydration" in Gormally, L., ed., The Dependent Elderly (Cambridge University Press, 1992).

Boyle, J. "Towards Ethical Guidelines for The use of Artificial Nutrition and Hydration" in Tollefsen, C., ed., Artificial Nutrition and Hydration: The New Catholic Debate (Springer, The Netherlands, 2008)

- Brink, P. "Issues of Reliability and Validity" in Morse, J. ed., Qualitative Nursing Research, 2nd ed. (Sage Publications, Newbury Park, 1991).
- Bryon, E., Dierckx de Casterlé, B., Gastmans, C. "Nurses' Attitudes Towards Artificial Food or Fluid Administration in Patients with Dementia and in Terminally Ill Patients: A Review of The Literature." Journal of Medical Ethics (2008) 34 [Online]. Available from: <http://jme.bmj.com> [Accessed 15 June, 2010].
- Burnard, P. "Interviewing," Nurse Researcher (RCN Publishing Company Ltd., Middlesex, 2005) 13 (1) 4-6.
- Cahill, L., "Bioethical Decisions to End Life." Theological Studies (1991) 52, 107-127
- Callaghan, S. "The Psychology of Emotions and the Ethics of Care" in Cates, D., Lauritzen, P., eds. Medicine and The Ethics of Care (Georgetown University Press, Washington, 2001)
- Calipari, M. "The Principle of Ethical Adequacy in The Use of Means of Preserving Life: Between Therapeutic Excess and Abandonment of The Patient." in Sgreccia, E., Laffitte, J., Alongside The Incurably Sick and Dying Person: Ethical and Practical Aspects (Libreria Editrice Vaticana, Città del Vaticano, 2009)
- Charmaz, K. "Grounded Theory: Objectivist and Constructivist Methods" in Denzin, N., Lincoln, Y., eds. Handbook of Qualitative Research, 2nd ed. (Sage Publications Ltd., Thousand Oaks, 2000) 509-535.
- Christians, C. "Ethics and Politics in Qualitative Research" in Denzin, N., Lincoln, Y., eds. Handbook of Qualitative Research, 2nd ed. (Sage Publications Ltd., Thousand Oaks, 2000) 133-155.
- Clarke, A. "Qualitative Interviewing: Encountering Ethical Issues and Challenges," Nurse Researcher (2006) 13 (4) 19-29.
- Clarke, C. "Ethics and the End of Life" In Holland, S. ed., Introducing Nursing Ethics: Themes In Theory and Practice (APS Publishing, Wiltshire, 2004).
- Cormack, D. "Gaining Access to The Research Site" in Cormack, D., ed. The Research Process in Nursing 4th ed. (Blackwell Sciences Ltd., London, 2000).
- Costello, J., "Dying Well: Nurses' Experiences of 'Good and Bad' Deaths in Hospital." Issues and Innovations in Nursing Practice (2005) 30 November, 594-601.
- Curran, C. "Evangelium vitae and Its Broader Context" in Curran, C., McCormick, A., eds. John Paul II and Moral Theology: Readings in Moral Theology, Series No. 10 (Paulist Press, New York, 1998).
- Cutcliffe, J., McKenna, H. "Expert Qualitative Researchers and the use of Audit Trails," Journal Of Advanced Nursing (2004) 45 (2) 126-133.

Daaleman, T., Usher, B., Williams, S., Rawlings, J., Hanson, L. "An Exploratory Study of Spiritual Care at The End of Life." Annals of Family Medicine [Online] (2008) 6 (5). Available from: <http://www.annfammed.org> [Accessed 7 December, 2009].

Davis, A., Slater, P. "U.S. and Australian Nurses' Attitudes and Beliefs about the Good Death." Journal of Nursing Scholarship (1989) 21 (1) 34-39.

Dearnley, C. "A Reflection on the use of Semi-Structured Interviews," Nurse Researcher (2005) 13 (1) 19-28.

De Beer, T., Gastmans, C., Dierckx de Casterlé, B. "Involvement of Nurses in Euthanasia: A Review of The Literature." Journal of Medical Ethics (2004) 30: 494-498

Deatrix J., Faux, S. "Conducting Qualitative Studies with Children and Adolescents" in Morse, J. , ed.,. Qualitative Nursing Research, 2nd ed., (Sage Publications Inc., Newbury Park, 1991).

Deffner, J., Bell, S. "Nurses' Death Anxiety, Comfort Level during Communication with Patients and Families Regarding Death, and Exposure to Communication Education: A Quantitative Study." Journal for Nurses in Staff Development [Online] (2005) 21 (91). Available from: <http://www.ncbi.nlm.nih.gov/pubmed/15731639> [Accessed 6 November, 2007].

Degnan, M. "Are We Morally Obligated to Feed PVS Patients till Natural Death?" in Tollefsen, C., ed., Artificial Nutrition and Hydration: The New Catholic Debate (Springer, The Netherlands, 2008).

Delany, M. "General Medical Practice: The Problem of Cooperation in Evil," in Watt, H. ed. Co-operation, Complicity and Conscience: Problems in Healthcare, Science, Law and Public Policy [The Linacre Centre, London, 2005].

Doerflinger, R., Gomez, C. "Killing the Pain, Not the Patient: Palliative Care vs. Assisted Suicide." [Online] Available from: <http://www.nccbuscc.org/prolife/programs/rlp/98rlpdoe.shtml> [Accessed 6 June, 2010].

Ersser, S., "Ethnography in Clinical Situations: An Ethical Appraisal" in de Raeve, L., ed.,. Nursing Research: An Ethical and Legal Appraisal (Baillière Tindall, London, 1996).

Field, P. "Doing Fieldwork in Your Own Culture" in, Morse, J. ed.,. Qualitative Nursing Research, 2nd ed., (Sage Publications Inc., Newbury Park, 1991) 91-104.

Finnis, J. "Bland: Crossing the Rubicon?" The Law Quarterly Review (1993) 109: 329-337.

Finnis, J. "Economics, Justice and The Value of Life: Concluding Remarks" in Gormally, L., ed., The Dependent Elderly (Cambridge University Press, Cambridge, 1992).

Finnis, J. "Euthanasia, Morality, and Law: Harry B. Burns Lecture, Loyola Marymount Law School, Los Angeles, California." [Online] (1996) November 22. Available from: <http://heinonline.org/HOL/LandingPage?collection=journals&handle...> [Accessed 7 May, 2010].

Fisher, A. "Why do Unresponsive Patients Still Matter?" in Tollefsen, C., ed., Artificial Nutrition and Hydration: The New Catholic Debate (Springer, The Netherlands, 2008).

Fontana, A., Frey, J. "The Interview" in Denzin, N., Lincoln, Y., eds. Handbook Of Qualitative Research, 2nd ed. (Sage Publications Ltd., Thousand Oaks, 2000).

Goodridge, D., Bond, J., Cameron, C., McKean, E. "End-of-Life Care in a Nursing Home: A Study of Family, Nurse and Healthcare Aide Perspectives." International Journal of Palliative Nursing (2005) 11 (5) 226-232.

Gormally, L. "Euthanasia and Assisted Suicide: Seven Reasons Why They Should Not be Legalised." [Online]. Available from: <http://www.linacre.org/newsle~1.htm> [Accessed 12 January, 2010].

Gormally, L. "Notes on The Winterton Bill." [Online] (2000). Available from: <http://www.linacre.org/winterton.html> [Accessed 10 March, 2010].

Gray, B., Smith, P. "Emotional Labour and The Clinical Settings of Nursing Care: The Perspectives of Nurses in East London." Nurse Education in Practice (2009) 9, 253-261.

Gray, B. "The Emotional Labour of Nursing – Defining and Managing Emotions in Nursing Work." Nurse Education Today (2009) 29: 168-175.

Gómez-Lobo, A. "Quality of Life and Assisted Nutrition" in Tollefsen, C., ed., Artificial Nutrition and Hydration: The New Catholic Debate (Springer, The Netherlands, 2008).

Gormally, L. "The Aged: Non-Persons, Human Dignity and Justice" in Gormally, L. ed., The Dependent Elderly: Autonomy, Justice and Quality of Care (Cambridge University Press, Cambridge, 1992).

Gormally, L. "The BMA Report on Euthanasia and The Case against Legalization" in Gormally, L., ed., Euthanasia, Clinical Practice and The Law (The Linacre Centre, London, 1994).

Gormally, L. "The Living Will: The Ethical Framework of A Recent Report" in Gormally, L., ed., The Dependent Elderly: Autonomy, Justice and Quality of Care (Cambridge University Press, Cambridge, 1992).

Gormally, L. "Why Not Dirty Your Hands" in, Watt, H. ed. Co-operation, Complicity and Conscience: Problems in Healthcare, Science, Law and Public Policy (The Linacre Centre, London, 2005).

Grisez, G. "Should Nutrition and Hydration be Provided to Permanently Unconscious and Other Mentally Disabled Persons?" in Hamel, P., Walters, J., eds., Artificial Nutrition and Hydration and The Permanently Unconscious Patient: The Catholic Debate (Georgetown University Press, Washington, 2007).

Kennedy, I., Grubb, A. "R. v Cox (1992) 12 BMLR38 (Winchester CC)." in Grubb, A., ed. Medical Law, 3rd ed. (Butterworths, London, 2000).

Hamel, R., Panicola, M. "Must We Preserve Life?" in Hamel, P., Walters, J., eds., Artificial Nutrition and Hydration and The Permanently Unconscious Patient: The Catholic Debate (Georgetown University Press, Washington, 2007).

Hellsten, S. "Towards an Alternative Approach to Personhood in The End-of-Life Questions." Theoretical Medicine, (Kluwer Academics Publishers, Netherlands, 2000).

Hickman, S. "Honoring Resident Autonomy In Long-Term Care: Special Considerations." Journal of Psychosocial Nursing and Mental Health Services [Online] (2004) 42 (1).

Hill, J., Seymour, J. "The Mental Capacity Act 2005: Making Decisions on Capacity." British Journal of Neuroscience Nursing (2010) 6 (4) 182-185.

Hohwy, J., Reutens, D. "A Case for Increased Caution in End-Of-Life Decisions for Disorders of Consciousness." Monash Bioethic Review [Online] (2009) 28 (2). Available from: <http://publications.epress.monash.edu> [Accessed 15 April, 2010].

Hollows, K. "The Lived Experience of Registered Nurses Involved in the Withdrawal of Nutrition and Hydration in a Persistent Vegetative State (PVS) Patient." Nursing Praxis in New Zealand (1995) 10 (1) 28-37.

Hopkinson, J. "The Hidden Benefit: The Supportive Function of The Nursing Handover for Qualified Nurses Caring for Dying People in Hospital." Journal of Clinical Nursing [Online] (2002) 11 (2). Available from: <http://gateway.uk.ovid.com/gw2/ovidweb.cgi> [Accessed 6 June, 2006].

Hoskins, S. "Nurses and National Socialism – A Moral Dilemma: One Historical Example of a Route to Euthanasia." Nursing Ethics (2005) 12 (1) 79-91.

Houtepen, R., Hendriks, D. "Nurses and the Virtues of Dealing With Existential Questions in Terminal Palliative Care." Nursing Ethics (2003) 10 (4) 377-388.

Hunter, B., Smith, P. "Emotional Labour: Just Another Buzz Word?" International Journal of Nursing Studies (2007) 44, 859-861.

Inghelbrecht, E., Bilsen, J., Mortier, F., Deliens, L. "The Role of Nurses in Physician-Assisted Deaths in Belgium" Canadian Medical Association Journal of Research [Online] (2010) May 17. Available from: www.cmaj.ca [Accessed 20 May, 2010].

- Janesick, V. "The Choreography of Qualitative Research Design" in Denzin, N., Lincoln, Y., eds., Handbook of Qualitative Research, 2nd ed. (Sage Publications Inc., California, 2000).
- Johnson, B., Plant, H. "Collecting Data from People with Cancer and Their Families: What are The Implications?" in De Raeve, L. Nursing Research: An Ethical and legal Appraisal (Ballière Tindall, London, 1996) 85-100.
- Kaveny, M. "Assisted Suicide, Euthanasia, and The Law." Theological Studies (1997) 58: 124-148.
- Kayser-Jones, J. "The Experience of Dying: An Ethnographic Nursing Home Study." The Gerontologist (2002) 42: 11-19.
- Keenan, J. "Assisted Suicide and The Distinction Between Killing and Letting Die." Catholic Medical Quarterly [Online] (May, 1992). Available from: http://www.catholicdoctors.org.uk/CMQ/May_1992/suicide_lettingdie.htm [Accessed 15 December, 2009].
- Kelly, D., Ross, S., Gray, B., Smith, P. "Death, Dying and Emotional Labour: Problematic Dimensions of The Bone Marrow Transplant Nursing Role?" Journal of Advanced Nursing (2000) 32 (4) 952-960.
- Kelly, G. "The Duty of Using Artificial Means of Preserving Life" Theological Studies (1950) 11: 203-220.
- Kelly, K., "Letter re Tony Bland Case," The Tablet (1992) 5 December: 246.
- Kelly, K., "Rest for Tony Bland," The Tablet (1993) 13 March: 247: 332-335.
- Kemmis, S., McTaggart, R. "Participatory Action Research" in Denzin, N., Lincoln, Y., eds., Handbook Of Qualitative Research, 2nd ed. (Sage Publications Inc., California, 2000).
- Kidd, D. tr., Nys, H., tr. "The Belgian Act on Euthanasia of May, 28th 2002," Ethical Perspectives [Online] (2002) 9 (2-3). Available from: <http://www.kuleuven.be/ep/viewpic.php?LAN=E&TABLE=EP&ID=59> [Accessed 5 September, 2009].
- Kirchoff, K., Beckstrand, L. "Critical Care Nurses' Perceptions of Obstacles and Helpful Behaviors in Providing End-of-Life Care to Dying Patients." American Association of Critical Care Nurses [Online] (1998). Available from: <http://classic.aacn.org/AACNjrnlaicc.nsf/0/7a18e54113c085b8882569050063cb2c?OpenDocument> [Accessed 19 December, 2009].
- Kirk, S. "The Value of Qualitative Research," [Online] (2009). Available from: <http://ezinearticles.com/?The-Value-of-Qualitative-Research&id=2026368> [Accessed 13 July, 2009].

Kitchener, B. "Nurse Characteristics and Attitudes to Active Voluntary Euthanasia: A Survey in The Australian Capital Territory." Journal of Advanced Nursing [Online] (1998) 28 (1). Available from: <http://gateway.uk.ovid.com/gw2/ovidweb.cgi> [Accessed 9 February 2001].

Koch, T. "The Difference that Difference Makes: Bioethics and The Challenge of Disability." Journal of Medicine and Philosophy (2004) 29 (6).

Kowalski, S.D. "Nevada Nurses' Attitudes Regarding Physician-Assisted Suicide." Clinical Nurse Specialist [Online] (1997) 11 (3). Available from: <http://gateway.uk.ovid.com/gw2/ovidweb.cgi> [Accessed 9 February, 2001].

Kuhse, H., Singer, P. "Voluntary Euthanasia and The Nurse: An Australian Survey." International Journal Nursing Studies (1993) 30.

Kutner, L. "Due Process of Euthanasia: The Living Will, A Proposal." Indiana Law Journal (1969) 539-554.

Kuuppelomäki, M. "Attitudes of Cancer Patients, Their Family Members and Health Professionals Toward Active Euthanasia." European Journal of Cancer Care (2000) 9: 16-21.

Lardy, H. "Analysis: Euthanasia and Euphemism: Law Hospital NHS Trust v Lord Advocate" The Edinburgh Law Review (1997) 1: 227-234.

Laing, J. "Food and Fluids: Human Law, Human Rights and Human Interests" in Tollefsen, C., ed., Artificial Nutrition and Hydration: The New Catholic Debate (Springer, The Netherlands, 2008).

Lee, P. "The Papal Allocution Concerning Care for PVS Patients: A Reply to Fr. O'Rourke" in Tollefsen, C., ed., Artificial Nutrition and Hydration: The New Catholic Debate (Springer, The Netherlands, 2008).

Lieberson, A. Treatment of Pain and Suffering in The Terminally Ill [Online] Available from: <http://preciouslegacy.com/> [Accessed 3 April, 2004].

Mahoney, J. "On a Human Right to Die," in, Hoose, B., Clague, J., Mannion, G., eds., Moral Theology for The twenty-First Century (T & T Clark Theology, London, 2008).

Materstvedt, L., Clark, D., Ellershaw, J., Førde, R., Gravgaard, A., Müller-Busch, H., Porta i Sales, J., Rapin, C. "Euthanasia and Physician-Assisted Suicide: A View From An EAPC Ethics Task Force." Palliative Medicine (2003) 97-101.

May, K. "Interview Techniques in Qualitative Research: Concerns and Challenges" in, Morse, J., ed., Qualitative Nursing Research: A Contemporary Dialogue, Revised ed., (Sage Publications, Inc. California, 1991).

- May, W. "Caring for Persons in The "Persistent Vegetative State" and Pope John Paul II's March 20 2004 Address "On Life-Sustaining Treatments and The Vegetative State" in Tollefsen, C., ed., Artificial Nutrition and Hydration: The New Catholic Debate (Springer, The Netherlands, 2008)
- May, W., Barry, R., Griese, O., Grisez, G., Johnstone, B., Marzen, T., McHugh, J., Meilander, G., Sieglar, M., Smith, W. "Feeding and Hydrating The Permanently Unconscious and Other Vulnerable Persons" in Caplan, A., McCartney, J., Sisti, D., eds. The Case of Terri Schiavo: Ethics at The End of Life. (Prometheus Books, New York, 2006.
- Mays, N., Pope, C. "Qualitative Research: Rigour and Qualitative Research" British Medical Journal [Online] (1995) 311. Available from: <http://www.bmj.com/cgi/content/extract/311/6997/109> [Accessed 9 June, 2009].
- McHaffie, H. "Ethical Issues in Research" in, Cormack, D., ed., The Research Process in Nursing, 4th ed. (Blackwell Sciences Ltd., London, 2000).
- McInerney, F., Seibold, C. "Nurses' Definitions of and Attitudes Towards Euthanasia." Journal of Advanced Nursing [Online] (1995) 22 (1). Available from: <http://gateway.uk.ovid.com/gw2/ovidweb.cgi> [Accessed 9 February, 2001].
- McNair, R., Taft, A., Hegarty, K. "Debate," BMC Medical Research Methodology (2008) 8:73 [Online]. Available from: <http://www.biomedcentral.com/1471-2288/8/73>. [Accessed 9 July, 2009].
- McSteen, K., Peden-McAlpine, C. "The Role of The Nurse as Advocate in Ethically Difficult Care Situations With Dying Patients." Journal of Hospice and Palliative Nursing [Online] (2006) 8 (05). Available from: <http://www.medscape.com/viewarticle/545616> [Accessed 7 December, 2009].
- Meilaender, G. "Ordinary and Extraordinary Treatments: When Does Quality of Life Count?" Theological Studies (1997) 58: 527-531.
- Milne, J., Oberle, K. "Enhancing Rigor in Qualitative Description," Journal of Wound Ostomy and Continence Nursing (2005) 32 (6) 413-420.
- Mok, E., Chui, P. "Nurse-Patient Relationships in Palliative Care." Journal of Advanced Nursing (2004) 48 (5).
- Moorman, S., Hauser, R., "Do Older Adults Know Their Spouses' End-Of-Life Treatment Preferences?" Research on Aging (2009) 31 (4) 463-491.
- Morse, J. "Strategies for Sampling" In, Morse, J., ed., Qualitative Nursing Research, 2nd ed., (Sage Publications Inc., Newbury Park, 1991).
- Muller, M., Pijnenbor, L., Onwuteaka-Philipsen, B., Van der Wal, G., Van Eijk, J. "The Role of The Nurse in Active Euthanasia and Physician-Assisted Suicide." Journal of Advanced Nursing [Online] (1997) 26 (2). Available from: <http://gateway.uk.ovid.com/gw2/ovidweb.cgi> [Accessed 9 February, 2001].

Munhall, P. "Institutional Review of Qualitative Research Proposals: A Task of No Small Consequence" In Morse, J., ed., Qualitative Nursing Research, 2nd ed., (Sage Publications Inc., Newbury Park, 1991).

Murray, D. "Co-operation, Complicity and Conscience: The Background to The Debate" in Watt, H., ed. Co-operation, Complicity and Conscience: Problems in Healthcare, Science, Law and Public Policy [The Linacre Centre, London, 2005]

Myers, R. "U.S. Law and Conscientious Objection in Healthcare" in Watt, H., ed. Co-operation, Complicity and Conscience: Problems in Healthcare, Science, Law and Public Policy [The Linacre Centre, London, 2005]

Mystakidou, K., Parpa, E., Katsouda, E., Galanos, A., Viahos, L. "Pain and Desire For Hastened Death In Terminally Ill Cancer Patients." Cancer Nursing (2005) 28 (4) 318-324.

O'Rourke, K. "Reflections on The Papal Allocution Concerning Care for Persistent Vegetative State Patients" in Hamel, P., Walters, J., eds., Artificial Nutrition and Hydration and The Permanently Unconscious Patient: The Catholic Debate (Georgetown University Press, Washington, 2007).

Paris, J., "Active Euthanasia." Theological Studies (1992) 53: 113-126.

Pellegrino, E. Decision at The End of Life: The Use and Abuse of The Concept of Futility [Online]. Available from: <http://www.ufl.org/vol10/pellegrino10.pdf> [Accessed 4 June, 2010].

Peters, E. "Hardt and O'Rourke Err in Minimizing The Scope of The CDF Response." The National Catholic Bioethics Quarterly (2008) 8 (1) 14-15.

Phillips, J., Davidson, p., Ollerton, R., Jackson, D., Kristjanson, L. "A Survey of Commitment and Compassion Among Nurses in Residential Aged Care." Journal of Palliative Nursing (2007) 13 (6) 282-290.

Pleschberger, S. "Dignity and The Challenge of Dying in Nursing Homes: The Residents' View." Age and Ageing (2007) 36: 1997-2002.

Pontin, D. "Interview" in, Cormack, D. ed., The Research Process in Nursing, 4th ed. (Blackwell Sciences Ltd., London, 2000) 289-299.

Reid, C.M., Gooberman-Hill, R., Hanks, G.W. "Opioid Analgesics for Cancer Pain: Symptom Control for the Living or Comfort for the Dying? A Qualitative Study to Investigate the Factors influencing the Decision to Accept Morphine for Pain Caused by Cancer." Annals of Oncology (2008) 19 (1) 44-48.

Rolfe, G. "Validity, Trustworthiness and Rigour: Quality and The Idea of Qualitative Research" Journal of Advanced Nursing [Online] 2006. Available from: <http://www.journalofadvancednursing.com/docs/1365-2648.2006.03727.x.pdf> [Accessed 9 June, 2009].

- Rogers, J. "Ethical Issues in Survey Research" in de Raeve, L. Nursing Research: An Ethical and Legal Appraisal (Baillière Tindall, London, 1996).
- Ryan, G., Bernard, H. "Data Management and Analysis Method" In, Denzin, N., Lincoln, Y., eds. Handbook of Qualitative Research, 2nd ed. (Sage Publications Ltd., Thousand Oaks, 2000).
- Ryan, G., Bernard, H. "Techniques to Identify Themes in Qualitative Data" [Online] Available from: http://www.analytictech.com/mb870/Readings/ryan-bernard_techniques_to_identify_the... [Accessed 20 October 2006].
- Sandelowski, M. "Focus on Research Methods: Whatever Happened to Qualitative Description?" Research In Nursing & Health (2000) 23, 334-340.
- Schnakers, C., Wanhaudenhuyse, A., Glacino, J., Ventura, M., Boly, M., Majerus, S., Moonen, G., Laureys, S. "Diagnostic Accuracy of The Vegetative and Minimally Conscious State: Clinical Consensus versus Standardized Neurobehavioural Assessment." BioMed Central (BMC) Neurology [Online] July 2009. Available from: <http://www.biomedcentral.com/1471-2377/9/35> [Accessed 9 December 2009].
- Schwarzenegger, C., Summers, S. "Criminal Law And Assisted Suicide In Switzerland: Hearing With The Select Committee On The Assisted Dying For The Terminally Ill Bill, House Of Lords." [Online] (2005) 3 February. Available from: <http://www.rwi.uzh.ch/lehreforschung/alphabetisch/schwarzenegger/publikationen/assisted-suicide-Switzerland.pdf> [Accessed 3 September 2009].
- Seale, C., Silverman, D. "Ensuring Rigour in Qualitative Research," European Journal of Public Health [Online] (1997) 7 (4). Available from: <http://eurpub.oxfordjournals.org/cgi/reprint/7/4/379> [Accessed 9 June 2009].
- Seymour, J., Janssens, R., Broeckaert, B. "Relieving Suffering at The End of Life: Practitioners' Perspectives on Palliative Sedation from Three European Countries." Social Science and Medicine (2007) 64: 1679-1691.
- Shannon, T., Walter, J. "Assisted Nutrition and Hydration and The Catholic Tradition." Theological Studies (2005) 66: 651-662.
- Shannon, T., Walter, J. "The PVS Patient and The Forgoing/Withdrawing of Medical Nutrition and Hydration" in Hamel, P., Walters, J., eds., Artificial Nutrition and Hydration and The Permanently Unconscious Patient: The Catholic Debate (Georgetown University Press, Washington, 2007).
- Sheehan, M. "Feeding Tubes: Sorting Out The Issues" in Hamel, R., Walter, J., eds., Artificial Nutrition and Hydration and The Permanently Unconscious Patient : The Catholic Debate (Georgetown University Press, Washington, 2007) 15-25
- Smith, P., Lorentzon, M. "Is Emotional Labour Ethical?" Nursing Ethics (2005) 12 (6) 638-642.

- Smith, P., Pearson, P., Ross, P. "Emotions at Work: What is The Link to Patient and Staff Safety? Implications for Nurse Managers in The NHS." Journal of Nursing Management (2009) 17, 230-237.
- Stern, P. "Are Counting and Coding A Capella Appropriate in Qualitative Research?" in, Morse, J., ed., Qualitative Nursing Research, 2nd ed., (Sage Publications, London, 1991).
- Tanida, N., Asai, A., Ohnishi, M., Nagata, S., Fukui, T., Yanazaki, Y., Kuhse, H. "Voluntary Active Euthanasia and The Nurse: A Comparison of Japanese and Australian Nurses." Nursing Ethics (2002) 9 (3).
- Tuckett, A. "Part II. Rigour in Qualitative Research: Complexities and Solutions," Nurse Researcher (2005) 13 (1) 29-42.
- Vacek, E. "The Emotions of Care in Health Care" in Cates, D., Lauritzen, P., eds. Medicine and The Ethics of Care (Georgetown University Press, Washington, 2001) .
- Valente, S. "End-of-Life Challenges: Honoring Autonomy." Cancer Nursing [Online] (2004) 27 (4). Available from: <http://www.medscape.com/viewarticle/487463> Accessed 9 June 2006.
- Van der Riet, P., Good, P., Higgins, I., Sneesby, L. "Palliative Care Professionals' Perceptions of Nutrition and Hydration at The end Of Life." International Journal of Palliative Nursing (2008) 14 (3) 145-151
- Van de Scheur, A., Van der Arend, A. "The Role of Nurses in Euthanasia: A Dutch Study." Nursing Ethics (1998) 5 (6).
- Van Manen, M., "Inquiry: Methodology." Phenomenology Online. [Online]. Available from: <http://www.phenomenologyonline.com/inquiry/9.html> [Accessed 2 November 2004].
- Van Manen, M. "Inquiry: Reductio." Phenomenology Online [Online]. Available from; <http://www.phenomenologyonline.com/inquiry/10.html> [Accessed 11 January, 2006].
- Van Manen, M. "Inquiry: Vocatio." Phenomenology Online [Online]. Available from: <http://www.phenomenologyonline.com/inquiry/17.html> [Accessed 11 January 2006].
- Van Wijmen, M., Rurup, M., Pasman, H., Kaspers, P., Onwuteaka-Philipsen, B. "Advance Directives in The Netherlands: An Empirical Contribution to The Exploration of A Cross-Cultural Perspective on Advance Directives." Bioethics (2010) 24 (3) 118-126.
- Verpoort, C., Gastmans, C., Dierckx de Casterlé, B. "Palliative Care Nurses' Views on Euthanasia." Journal of Advanced Nursing (2004) 47 (6).

Watson, J., Hockley, J., Dewar, B. "Barriers to Implementing an Integrated Care Pathway for The Last Days of Life in Nursing Homes." International journal of Palliative Nursing (2006) 12 (6) 234-240.

Watt, H. "Cooperation Problems in Care of Suicidal Patients" in Watt, H. ed. Co-operation, Complicity and Conscience: Problems in Healthcare, Science, Law and Public Policy [The Linacre Centre, London, 2005]

Watt, H. "Euthanasia: Unpacking the Debate" (The Linacre Centre for Healthcare Ethics, London, 2002) [Online]. Available from: <http://www.linacre.org/euunde.html> [Accessed 12 January 2010].

Watt, H. "The Case Against Assisted Dying" (The Linacre Centre for Healthcare Ethics, London, 2008) [Online]. Available from: <http://www.linacre.org/CaseAgainstAsstDying.htm> [Accessed 12 January 2010].

Young, M.G. Ogden, R.D. "End of Life Issues: A Survey of English-Speaking Canadian Nurses in AIDS care. Journal of The Association of Nurses in AIDS Care (1998) 9 (2).



M E M O R A N D U M

HUMAN PARTICIPANTS AND MATERIALS ETHICAL COMMITTEE

FROM: John Oates, Chair, HPMEC **Email:** j.m.oates@open.ac.uk
TO: Sylvia A. Hoskins, Higher Degree student at Maryvale Institute, Birmingham, under OU sponsorship scheme. **TEL:** 52395
CC: **DATE:** 1 June 2004
SUBJECT: **Ethics application:** The legalization of euthanasia: the impact on nurses and their practice **Ref:** HPMEC/04/#73/1

This memorandum is to confirm that the research protocol and supporting documentation for the above-named research project, as revised and submitted on 20th May 2004, are approved by the Open University Human Participants and Materials Ethical Committee, subject to agreement to the two changes requested below.

It is felt that your own views on the topic under investigation are a potential source of bias and the research protocol should be designed to minimize such effects. In particular, the scrutineers felt that the 'ban' on discussing euthanasia that you propose (page 13, para. 2), and the associated termination of interviews where the term is raised, runs a high risk of excluding data that might give a balanced view of respondents' attitudes. Attitudes in this area are not the same kind as behaviour, and are not legislated against in the United Kingdom.

In consequence you are asked to make the two following changes:

- 1) Amend the sentence referred to above to "If the participant raises the concept of euthanasia in a general sense, they will be reminded that the purpose of the interview is to explore their experiences of decision-making in end-of-life care".
- 2) Amend the information sheet to state "Euthanasia will not be discussed unless it was raised in a particular case by, for example, a patient or relative".

I would be grateful if you could inform me of your agreement to these changes, or if you have reasons to disagree with them, to state these in writing.

John Oates

Chair, OU HPMEC

Sylvia Hoskins (FNSSH)

From: J.M.Oates [J.M.Oates@open.ac.uk]
Sent: 29 June 2004 11:47
To: Sylvia Hoskins (FNSSH)
Subject: RE: Your Ref: HPMEC/O4 73/1

Dear Sylvia Hoskins,

Thank you for your response, which clearly confirms your agreement to follow the recommendations of the HPMEC in respect of your research project.

Hence your protocol now has full approval.

I wish you every success with your study and hope to receive a summary report following its conclusion. Please contact the secretary to HPMEC, Carmel Collins (c.collins@open.ac.uk) or myself if any ethical issues arise in the course of your project that are not covered by the protocol, or if you wish to significantly revise any aspects.

John Oates
Chair, HPMEC.

LETTER OF INVITATION TO GATEKEEPER

October 18, 2004.

Mrs. xxxx Manager,
xxxxxxx Care Home
xxxxxxxxxx.

Dear xxxxxxx,

**Research: The Legalisation of Euthanasia
The Impact on Nurses and Their Practice**

A Nursing and Moral Theological Study.

An exploration of nurses' experiences of how decisions are made on end-of-life care in private care homes and a discussion on how the legalisation of euthanasia could impact on the nurse's role in caring for the client, in the light of Christian Moral Principles

Request for your services to invite a volunteer registered nurse (a member of your staff) to participate in a research study.

Whilst working as a lecturer at xxxxxxxxxxxxxxxx University, I have been involved in a research study (see attached protocol) for the past three years, working towards a Doctorate in Philosophy. As the research is both Nursing and Moral Theology, I have been undertaking the research through the Maryvale Institute in Birmingham, a Theological Institute which is affiliated to The Open University.

The Open University Ethics Committee have now given me ethical clearance (see Ethical Clearance form and attachment) to interview one nurse from twenty care homes in the north of Scotland.

I am seeking to recruit a nurse from your care home who would **volunteer** to participate in the research study.

Would you consider offering your services as "Gatekeeper", someone who will ensure that any participant is a volunteer and **is not known to me**? It is important for the protection of the nurse and me that a Gatekeeper supervises the recruitment of a registered nurse. It is important that I don't know that nurse. If I recognise the nurse at the interview, then I would have to terminate the interview process.

If you agree, I would wish to interview that nurse in a setting that is conducive to the nurse and to you and I would hope that after you approached the nurse and sought her agreement to participate, you would arrange for the interview time and place to be undertaken somewhere private within the care home **during the month of November, 2004.**

If you give permission for me to interview a nurse, what I would like you to do is:

1. **Read the enclosed protocol.** This explains the entire research process and the ethical implications of an interview.
2. **Ethical clearance** If you consider that the research is appropriate and ethically sound (refer to The Open University Ethics Committee memorandum of June 1st, 2004), please sign the enclosed “Ethical clearance form” and return it to me in the enclosed pre-addressed/pre-paid envelope.
3. **Identify and approach one registered nurses** currently working in your care home who might wish to participate in the study. Ask if he/she would consider participating in a research study and be interviewed. This is a voluntary process and the nurse must not feel coerced in any way. If the nurse refuses, please approach another nurse with the same request.

4. **Give the nurse the package containing:**

- ☐ The letter of invitation (white).
- ☐ The Information Sheet (mauve).
- ☐ The Interview guide (yellow).
- ☐ The consent form agreeing to participate (salmon pink).
- ☐ The consent form agreeing for use of an audiotape (blue).
- ☐ The form guaranteeing non-duplication of audiotapes (green).

6. **Allow the nurse seven days** to read the information and tell the nurse that you will ask in seven days if he/she wishes to participate in the research study.
 - ☐ After 7 days, contact the nurse and ask if he/she would like to participate in the research study.
 - ☐ If the answer is “no,” do not inform me. Only inform me of the nurse who says “yes”.
 - ☐ **If the answer is yes, liaise with the nurse and me** to set up an appropriate interview time and place during the month of November, 2004.
 - ☐ I would appreciate it if the interview could take place within the care home in a private area. This gives security and privacy to the nurse and me.
 - ☐ I would like also to request that you introduce the volunteer to me personally and witness the signature of the three forms: 1. agreement to participate; 2. agreement to use audiotape; 3. form guaranteeing non-duplication of audiotapes.

Ask the Volunteer Nurse if there are any questions he/she would like to ask me prior to the interview, anything that might influence the decision to participate. Please contact me if this is the situation.

- ❖ Please assure him/her that this is voluntary and is not related to their current employment situation. Assure the nurse that the research study is confidential and anonymous and names will not be used in the research study – only for signing the consent forms (these forms will be destroyed when the research is completed). Each nurse's data will be given a number to guarantee anonymity.

You will find attached **a copy of the Research Protocol**. This is to inform you of the Research process. I ask that you keep this confidential and return it to me after you have read it.

Also enclosed is: **An ethical clearance form (white) for you to sign and return to me in the envelope enclosed, prior to my contact with the nurse.**

If you would like to discuss the research with me, please contact me on xxxxxxxxxxxx or my mobile: xxxxxxxxxxxx so that an appointment can be arranged where we could discuss this at the care home.

However, if you do not wish to see me personally and you have any questions you would like to ask me prior to identifying a nurse, please contact me on the same telephone contact numbers. I look forward to hearing from you and would appreciate it if you would contact me by November 1, 2004, for a possible interview with the volunteer nurse, during the month of November.

Thank you for assisting me with the research study.

Yours sincerely,

Mrs. Sylvia A. Hoskins
M.Ed, BSc (Hons), SRN, RMN, RCNT, NT.
Lecturer in Nursing.

October 18, 2004.

**Invitation to take part in a
Research Pilot Interview**

Dear Colleague,

Research: The Legalisation of Euthanasia
The Impact on Nurses and Their Practice

A Nursing and Moral Theological Study

An exploration of nurses' experiences of how decisions are made on end-of-life care in private care homes and a discussion on how the legalisation of euthanasia could impact on the nurses' role in caring for the client, in the light of Christian Moral Principles

- ❖ I am inviting you to participate in a research study that is of considerable importance to the Nursing profession.
- ❖ The research study is about exploring nurses' experiences on how decisions are made on end-of-life care in private care homes.
- ❖ I would like to interview you and find out what your experiences are on this topic. Once I have the information, I am going to analyse the information and extract the issues relevant to nursing.
- ❖ I will then discuss how the legalisation of euthanasia could impact on the nurses' role in caring for the client. This will be discussed in the light of Christian Moral Principles and presented as a PhD Thesis.

- ❖ **I do not know your name.** I have asked a colleague to seek a volunteer for this study. This allows you the freedom to choose without any coercion.

CONSENT, CONFIDENTIALITY AND ANONYMITY

- ❖ **The research study is confidential and guarantees your anonymity.** If you agree to participate, I will only need to know your name for the purpose of the consent form. (This will be shredded when the study is completed). Your name will not be used in the study, as your data will be given a number. Your address is not asked for or required. Also details of your circumstances at work will **not** be discussed in the study only that you, the participant, work in a care home. This ensures that participating in the research study is **totally confidential and anonymous**.
- ❖ **Your consent** to participate freely in the research study is required and you will need to sign a consent form prior to the interview being undertaken.
- ❖ **Your consent** is also required if you agree to an audiotape being used in the interview. This is not mandatory and is not a requirement of the interview process. If you prefer not to speak into an audiotape, that is perfectly acceptable.
- ❖ The research study is also **completely voluntary** and at no stage should you feel any pressure to respond to the invitation to be part of the research study.

What I would like you to do is:

1. **Read the Information Sheet** (mauve paper) attached to this invitation explaining the nature of the study.
2. **Read the Interview Guide** (yellow paper) giving a general idea of areas to consider.
3. **Read the Consent form** (Salmon pink paper) to understand what you are consenting to. Do not sign the form at this point
4. **Read the Audiotape Consent Form** (blue paper). Do not sign the form at this point.
5. **Read the “Guarantee that the Audiotape will not be duplicated** (green paper). Do not sign the form.

Then

1. **Inform the nurse who contacted you** If you agree to participate in the study and you agree to being interviewed by me.
2. **Appointment** This nurse will **only** contact me and inform me if you have agreed to be interviewed. The nurse will then liaise with you to set up a suitable time and place for an interview to be undertaken. This will take place within the care home.
3. **Time**: I do not envisage this interview taking any longer than **One hour**, but you are free to stop the interview **at any time**.
4. **Data**: You are also free to ask for the destruction of all or any of the data at any time.

Explanation of the Research Interview

- ❖ **The research interview is structured to:**
- ❖ Explain the research study again and answer any of your questions.
- ❖ Ask you to sign a **consent form** (salmon pink). This will be witnessed and signed by the nurse who contacted you and who will introduce me to you.
- ❖ Ask you to sign **an agreement for use of an audiotape form** (blue). This will be witnessed and signed by the nurse who contacted you and who will introduce me to you.
- ❖ Encourage you to talk freely about your experiences on decision-making on end-of-life care.
- ❖ Gather data (your words) by taking me taking notes.
- ❖ If you agree, record your words on an audiotape. This will be wiped out at the end of the research study in your presence and the blank tape will be given to you.
- ❖ **I will sign the "Guarantee that The Audiotape will not be duplicated"** (green form) and give you the form.

Purpose of the Study

The research survey is part of a PhD research project, which I am undertaking on a part-time basis. My ultimate aim in undertaking this study is to promote good nursing practice in order to ensure the highest quality care for clients in care homes.

As nurses, we are accountable to a 'Code of Professional Conduct.' If euthanasia were to be made legal in the United Kingdom, nurses could face significant changes in their role in caring for clients and patients.

It is important that we reflect and debate the issues concerning decision making on end-of-life care, at a time when euthanasia is not legal in the United Kingdom, but where the current trend in the European Union is moving towards the legalisation of euthanasia.

This research will encourage nurses to reflect on the moral and ethical implications for nursing practice if euthanasia were to be made legal in the United Kingdom.

My name, qualifications and position

My name is Mrs. Sylvia Anne Hoskins. I am xx years old and have been qualified as a nurse since xxxx. My qualifications are as follows:

<input type="checkbox"/> Master of Education (Religious Education)	-	M.Ed.
<input type="checkbox"/> Bachelor of Science Degree (Hons) in Nursing	-	BSc (Hons)
<input type="checkbox"/> State Registered Nurse	-	SRN
<input type="checkbox"/> Registered Mental Nurse	-	RMN
<input type="checkbox"/> Registered Clinical Nurse Teacher	-	RCNT
<input type="checkbox"/> Registered Nurse Tutor (RNT)	-	RNT

I am a university lecturer in nursing and my speciality is care of the elderly person.

The study is taking place under the auspices of:

- ❖ **Maryvale Institute in Birmingham (A Theological Institute).**
- ❖ **The Open University.**

Risks and side effects of participation in the research interview

I am conscious of the fact that this may be an emotionally sensitive subject to you. There is a risk that reading the subject title and/or participating in the interview may trigger memories that are distressing to you.

If you are concerned that the subject area would be emotionally difficult to deal with and may have the potential to cause you emotional harm, then I must advise you that:

You should not participate in the research study.

If you consider that participating in the research study may cause you some distress **but you still wish to be interviewed by me**, then I advise you to seek guidance and advice from your **General Practitioner (family doctor)** to advise on any potential psychological consequences of participation.

If you decide to participate in the research survey and after being interviewed by me you find that you are upset in any way, I advise you to contact your **General Practitioner (family doctor)** immediately.

If you would like to talk to someone, you can call the Samaritans –a National 24 hour confidential service. Telephone: UK: 08457 90 90 90; Ireland: 1850 60 90 90.

If you have any comments or complaints about the research study

You can contact:

1. **The researcher (me):** Mrs. Sylvia Anne Hoskins
Research Department,
Maryvale Institute,
Old Oscott Hill,
Kingstanding,
Birmingham,
B44-9AG.

Email: research.Maryvale@dial.pipex.com; **Tel:** xxxxxxxxxxxxxxxx

2. **The Director of Research Studies:** Professor xxxxxxxxxxxx
Research Department
Maryvale Institute,
Old Oscott Hill,
Kingstanding,
Birmingham,
B44-9AG.

Tel: 0121-360-8118.

What will happen to the Information?

- ❖ The information from the interview will be inputted into my computer and the data analysed. The data will be protected on the computer and I will be the only person who will have access to it.
- ❖ I will use the analysed information to discuss the moral and ethical issues for Nurses on end-of-life care if euthanasia were to be made legal in the United Kingdom. This will be discussed in the light of Christian Moral Principles.
- ❖ This will be presented in the form of a PhD thesis.
- ❖ At the end of the research study:
 1. The data in my computer will be destroyed by overwriting it at least seven times.
 2. The audiotape (if used) will be erased in your presence and the blank tape will be given to you.
 3. The consent forms with your name and signature will be shredded in a shredding machine.

Where will the results be published?

- ❖ The research results will be distributed through published papers, talks at conferences and lectures with the purpose of encouraging debate throughout the nursing profession on decision-making on end-of-life care. However, as the data will be anonymous, it will be impossible to identify you in any way.
- ❖ It will also be published in the theological community because it is a Nursing and Moral Theology Study.
- ❖ The entire thesis will be available through the Maryvale Institute.
- ❖ Once the research results are ready for publication, I will inform the participants of the research study, first.
- ❖ I will then notify all nurses by placing a notice on the Nursing and Midwifery Council (NMC) Website.

On reading the information sheet

- ❖ **Inform the nurse who contacted you:** of your decision, whether you wish to accept or decline my invitation to take part in the research study.
- ❖ **You are free to choose.** There is no requirement to participate.

Thank you very much for taking the time to read the invitation and the Information Sheet.

Yours sincerely,

Sylvia Anne Hoskins

November 1, 2004.

**Invitation to Take Part in A
Research Study of Nurses**

Dear Colleague,

Research: The Legalisation of Euthanasia
The Impact on Nurses and Their Practice

A Nursing and Moral Theological Study

An exploration of nurses' experiences of how decisions are made on end-of-life care in private care homes and a discussion on how the legalisation of euthanasia could impact on the nurses' role in caring for the client, in the light of Christian Moral Principles

- ❖ I am inviting you to participate in a research study that is of considerable importance to the Nursing profession.
- ❖ The research study is about exploring nurses' experiences on how decisions are made on end-of-life care in private care homes.
- ❖ I would like to interview you and find out what your experiences are on this topic. Once I have the information, I am going to analyse the information and extract the issues relevant to nursing.
- ❖ I will then discuss how the legalisation of euthanasia could impact on the nurses' role in caring for the client. This will be discussed in the light of Christian Moral Principles and presented as a PhD Thesis.

- ❖ **I do not know your name.** I have asked a colleague to seek a volunteer for this study. This allows you the freedom to choose without any coercion.

Information Sheet

End-of-Life care refers to the care given in the final weeks of a person's life where death is seen to be imminent.

The purpose of the research is to explore nurses' experiences of how decisions are made on end-of-life care in private care homes; to discuss how the legalisation of euthanasia could impact on that decision making process and the nurses' role in caring for the client, in the light of Christian moral principles.

Against the backdrop of the Nursing and Midwifery Council (NMC) Code of Professional Conduct (2002), the question must be asked, if euthanasia were to be made legal in the United Kingdom, what impact would it have on nurses and their practice, in the light of Christian moral principles.

Your invitation

I have invited you to take part in this research study and wish to inform you of the following:

- ❖ This is an anonymous and confidential study.
- ❖ You are a volunteer. There is no pressure on you to participate.
- ❖ You will be one of 20 nurses invited to participate in the study.
- ❖ The interview will be undertaken in a privately designated place within the care home, suitable to you.

The Boundaries of the Interview.

- ❖ Nothing other than your experiences of decision-making on end-of-life care is to be discussed.
- ❖ Euthanasia will not be discussed unless it was raised in a particular case by a patient or relative, for example.
- ❖ If a crime is confessed with regard to euthanasia, the researcher will have a duty to inform the police.
- ❖ Names of third parties must not be given.
- ❖ Establishment names must not be given.
- ❖ You must not make any defamatory statements about a third party, which you believe to be untrue or even damaging to that person. As the researcher and interviewer, I will not be making or using any defamatory statements
- ❖ If this happens the information will be eradicated.
- ❖ Any care issues with regard to the care home cannot be discussed; otherwise I will have a duty to inform the Manager of the home.

Control of research findings

Whilst I have taken every precaution to ensure that the dissemination of the research results is within the boundaries of the nursing and theological communities, it may not be possible for me to control the dissemination of the research results entirely. It is important that you are aware of this fact before making any decision to participate in the research study. However, because your name, address or details of your work circumstances **will not be used**, the research will be completely anonymous. This will be possible because I will give your data a **number**.

The interview

The interview will focus on **end-of-life issues** but it is important that you are aware of the following definitions of what end-of-life issues can include and what is **NOT** considered to be euthanasia in terms of the United Kingdom Law and the moral laws. Euthanasia is illegal in the United Kingdom and will not be discussed; however, in order that you are fully informed and understand the meaning of the term “euthanasia” I have included this for your information.

Before we start the interview process

- ❖ It is important that you are absolutely clear about all aspects of this study.
- ❖ Before the interview starts, I will re-iterate the purpose of the study to you and then give you the opportunity to ask any questions. You must feel free to clarify any points before we start the interview.
- ❖ Consent must be informed and therefore you should have all the facts and figures available to you before you sign the Consent form agreeing to participate in the research study. I will ask you to sign the Consent form prior to the interview.
- ❖ You must also give consent if you agree to an audiotape being used during the interview. This is not mandatory and does not affect the interview process. If you decide you do not wish an audiotape to be used during the interview, this is perfectly acceptable.
- ❖ I will ask the third party to witness the signatures on both forms.
- ❖ I will also give you a signed form, guaranteeing that in the event an audiotape is used, the material will not be duplicated. I will ask the third party to witness my signature on this form.

During the Interview

- ❖ You can terminate the interview at any time.
- ❖ You will not be asked to continue and your request will be respected immediately.
- ❖ You also have the right to ask for the destruction of any or all of the data that you have provided, at any time.
- ❖ You can ask for clarification of any point discussed.
- ❖ If, after the interview, you regret having participated and do not want your words to be used, you must contact me immediately. You are free to halt participation in the study at any time. If this happens, all your data will be destroyed immediately.
- ❖ This process is a matter of mutual respect and emphasises the control that you have over the research study.



Some of the Issues related to End-of-life Care

Pain

- ☐ The nature of pain; Measuring pain.
- ☐ Pain therapy using different routes of administration.
- ☐ Alternative therapies for pain (e.g. massage, acupuncture).

Suffering

- ☐ End of stage physical suffering.
- ☐ Mental suffering.
- ☐ Effects of suffering on others.
- ☐ Adapting to the reality of death.

Suffering from Physical Symptoms (other than pain)

- ☐ Nausea and vomiting
- ☐ Constipation or diarrhoea.
- ☐ Loss of appetite; Difficulty in swallowing.
- ☐ Dry mouth.
- ☐ Nutrition and hydration.
- ☐ Breathing problems.
- ☐ Difficulty in sleeping.
- ☐ Skin – itching, bedsores, oedema.
- ☐ Bladder problems.
- ☐ General weakness.

Mental Suffering

- ☐ Anxiety; depression.
- ☐ Fear – pain, death, being a burden on others, abandonment, loss of status, losing mental ability, being or being considered worthless.
- ☐ Inability to control body functions – loss of dignity.
- ☐ Sense of hopelessness; grief.
- ☐ Loss of privacy.

Nurse's role.

- ☐ **Being there;** Showing compassion
- ☐ **Spiritual care** – making sense of the situation, giving hope, helping to find peace, involvement of spiritual carer (e.g. priest, minister).
- ☐ Working through problems.
- ☐ Honouring privacy.
- ☐ Tender loving care.
- ☐ Appropriate physical and mental care.
- ☐ Nutrition and hydration.
- ☐ **Family issues** (pain, suffering, pressure, dying at home).
- ☐ **Family intervention** – demands for futile therapy, concerns in stopping aggressive therapy, requests for assisted suicide.
- ☐ **Family** – Decision-making for relatives with Alzheimer's disease.
- ☐ **Family-** Grief, anger, mourning, loss.

[Lieberson, A. "Treatment of Pain and Suffering in the Terminally ill" [online]
Available at: <http://www.preciouslegacy.com>]

Clarification of Terminology

What is NOT considered as Euthanasia

The Catechism of the Catholic Church states:

2278 Discontinuing medical procedures that are burdensome, dangerous, extraordinary, or disproportionate to the expected outcome can be legitimate; it is the refusal of “over-zealous” treatment. Here one does not will to cause death; one’s inability to impede it is merely accepted. The decisions should be made by the patient if he is competent and able or, if not, by those legally entitled to act for the patient, whose reasonable will and legitimate interests must always be respected.

2279 Even if death is thought imminent, the ordinary care owed to a sick person cannot be legitimately interrupted. The use of painkillers to alleviate the sufferings of the dying, even at the risk of shortening their days can be morally in conformity with human dignity if death is not willed as either an end or a means, but only foreseen and tolerated as inevitable.

Catechism of the Catholic Church. (Burns & Oates, London, 1999).

Madden (2002) states:

(11.136) In the treatment of certain illnesses, such as cancer, it sometimes becomes necessary to administer large doses of pain killing drugs to ease the patient’s suffering. These drugs may carry higher risks of causing respiratory depression and hastening the patient’s death. Most would agree that not to administer such drugs would result in unacceptable pain for the dying patient; therefore the actions of the doctor are justified on the basis of his intention to relieve suffering as opposed to bring on the patient’s death.

Madden, D. Medicine, Ethics and The Law (Butterworth Ltd., Dublin, 2002) 530.

Meaning of the term “Euthanasia”.

Euthanasia is understood as an action or an omission, which of itself or by intention causes death, in order that all suffering may in this way be eliminated. Euthanasia's term of references, therefore, are to be found in the intention of the will and in the methods used.

Sacred Congregation for The Doctrine of The Faith. Jura et Bona (5 May 1980) in Flannery, A., ed. Vatican Council II. Vol. 2., Revised Edition, (Costello Publishing Company, New York, 1998).

In Medical Law: euthanasia can be classified as:

1. Involuntary (against the wishes of a competent person).
2. Voluntary (with the wishes of a competent person).
3. Non-voluntary (where the individual is incompetent).
 - ☐ Active (a positive act that causes the death) or
 - ☐ Passive (an omission or failure to act).

Maclea, A. Briefcase on Medical Law. (Cavendish Publishing, London, 2001) 93.

Interview Guide

- ❖ **I want you to tell me about your experience/s of decision-making in end-of-life care whilst working in a private care home.**
- ❖ **You can talk about anything you want**, but just to get you started, here are some things you might want to consider – they are nothing more than triggers for your memory. **Have a think about them.**

- ❖ You may wish to refer back to the Information Sheet to remind yourself of some of the issues with end-of-life-care.

- ❖ **This can be:**
 - How you care for your clients/patients when they are dying.
 - How you worked with the rest of the staff.
- ❖ **It can include**
 - How you felt.
 - A happy experience.
 - A sad experience.
- ❖ **The clients/patients**
 - About their illness.
 - How you think they felt.
 - If they said anything to you.
- ❖ **The Relatives:**
 - How you think they felt.
 - What they wanted for their relative.
 - What they might have said to you.
- ❖ **The Decisions**
 - How the decisions were made.
 - Who made the final decisions about care?

Anything that you want to bring to the experience. You may not even want to include any of these things; they are triggers to start your reflective process.

YOU WILL

- ❖ Be talking about **your experiences** of decision-making on end-of-life care.
- ❖ Be talking freely.
- ❖ Be talking in confidence.
- ❖ Be confident in the knowledge that your data will be used anonymously and that no-one will be able to identify you in the research study.

CONSENT – AGREEMENT TO PARTICIPATE

Maryvale Institute – Research Department

Title of Research - “The Legalisation of Euthanasia: The Impact on Nurses and Their Practice”.

A Nursing and Moral Theological Study

An exploration of nurses’ experiences of how decisions are made on end-of-life care in private care homes and a discussion on how the legalisation of euthanasia could impact on the nurses’ role in caring for the client,
in the light of Christian Moral Principles

Agreement to Participate:

(Print Name) I,

Agree to take part in this research project.

- ☐ I have had the purposes of the research project explained to me.
- ☐ I have been informed that I may refuse to participate at any point by simply saying so.
- ☐ I have been informed that I have the right to ask for the destruction of any or all of the data that I have provided, at any time.
- ☐ I have been assured that my confidentiality and anonymity will be totally protected as specified in the Invitation Letter and the Information Sheet.
- ☐ I agree I have also been assured that I cannot be identified through details of my work circumstances and that the researcher will only use the fact that I work in a care home.
- ☐ That the information that I provide can be used for educational or research purposes, including publication.
- ☐ I understand that if I have any concerns or difficulties I can contact:

Mrs. Sylvia Hoskins

Maryvale Institute, Research Department.
Old Oscott Hill, Kingstanding, Birmingham,
B44-9AG. Tel: xxxxxxxxxx
Email: research.Maryvale@dial.pipex.com

If I wish to complain about any aspect of my participation in this project, I can contact the Director of Research at:

Professor xxxxxxxxxxxxxxxxxxxxxxxxxxxxxxxxx
Research Department, Maryvale Institute,
Old Oscott Hill, Kingstanding, Birmingham,
B44-9AG. Tel: 0121-360-8118.

This research, conducted under the auspices of the Maryvale Institute and of the Open University, will be used in education, research and publication.

Signed:

Date:

Witness:

Date:

**CONSENT – AGREEMENT FOR USE OF AN AUDIOTAPE DURING THE
RESEARCH INTERVIEW PROCESS.**

Maryvale Institute – Research Department

Title of Research - “The Legalisation of Euthanasia: The Impact on Nurses and Their Practice”.

A Nursing and Moral Theological Study

An exploration of nurses’ experiences of how decisions are made on end-of-life care in private care homes and a discussion on how the legalisation of euthanasia could impact on the nurses’ role in caring for the client,
in the light of Christian Moral Principles

Agreement for use of an Audiotape during the Research Interview Process:

(Print Name) I,

Agree that the researcher may use an Audiotape during the Research Interview Process..

- I have had the purposes of the Audiotape explained to me; that this will only be used to verify the written data, taken by the researcher, during the interview.
- I have been informed that I may refuse to agree to an audiotape being used in the research interview.
- I have been informed that if I do not agree to the use of an audiotape during the research interview process, this is perfectly acceptable and does not affect the research process.
- I have been informed that I have the right to ask for the destruction of any or all of the data that I have provided at any time and that this includes the audiotape.
- I have been assured that my confidentiality and anonymity will be totally protected as specified in the Invitation Letter and the Information Sheet and that the researcher will not use my name at any point in the research process.
- I have also been assured that I cannot be identified through details of my work circumstances and that the researcher will only use the fact that I work in a care home.
- I have been assured that after the data are analysed and the research study is completed, that the audiotape will be erased in my presence and the blank tape will be given to me.
- I have been given a signed form by the researcher guaranteeing that there will be no duplication of the audiotape.

- I agree that the information that I provide on the audiotape can be used for educational or research purposes, including publication.
- I understand that if I have any concerns or difficulties I can contact:

Mrs. Sylvia Hoskins

Maryvale Institute, Research Department. Old Oscott Hill, Kingstanding, Birmingham, B44-9AG. Tel: xxxxxxxxxx Email: research.Maryvale@dial.pipex.com
--

If I wish to complain about any aspect of my participation in this project, I can contact the Director of Research at:

Professor xxxxxxxxxxxxxxxxx Maryvale Institute, Research Department, Old Oscott Hill, Kingstanding, Birmingham, B44-9AG. Tel: 0121-360-8118

This research, conducted under the auspices of the Maryvale Institute and of the Open University, will be used in education research and publication.

Signed:

Date:

Witnesss

Date:

GUARANTEE THAT THE AUDIOTAPE WILL NOT BE DUPLICATED.

Maryvale Institute – Research Department.

Title of Research - “The Legalisation of Euthanasia: The Impact on Nurses and Their Practice”.

A Nursing and Moral Theological Study

An exploration of nurses’ experiences of how decisions are made on end-of-life care in private care homes and a discussion on how the legalisation of euthanasia could impact on the nurses’ role in caring for the client,

in the light of Christian Moral Principles

(Print Name) I,

- ❖ That in agreement for use of an audiotape during the research interview process
- ❖ Will guarantee that the audiotape used in the research interview will not be duplicated.
- ❖ Will ensure that the purposes that the data will be used will only be as agreed between the researcher and the participant.
- ❖ That at the end of the research study, the audiotape will be erased in the presence of the participant and the blank tape will be given to the participant.
- ❖ I guarantee total protection of confidentiality and anonymity and that the participant will not be identified through the use of an audiotape.

Name: Mrs. Sylvia Anne Hoskins.

**Sig
ned:**

Date:

Witness:**Date:**.....

ETHICAL CLEARANCE

I,

PRINT NAME:

1. **Have read the research protocol: “The Legalisation of Euthanasia – The Impact on Nurses and Their Practice”.**
2. **Am aware that this is a private study and not sponsored by any Company or individual person.**
3. **Am aware that this is a nursing and moral theological study; that it is an exploration of nurses’ experiences of how decisions are made on end-of-life care in private care homes and that the results of the interviews will be used to discuss how the legalisation of euthanasia could impact on the nurses’ role in caring for the client; and that this will be discussed from a Christian Moral point of view.**
4. **Am satisfied that the researcher has considered all ethical issues.**
5. **Am satisfied that the researcher has considered all measures of safety.**
6. **Am satisfied that the researcher has ensured complete confidentiality and anonymity to the participant.**
7. **That no anticipated harm will come to the nurse participating with the research study.**
8. **That I will personally witness and sign the nurse’s consent form and consent for use of audiotape form (if agreed by the volunteer nurse) to ensure that the nurse is a consenting volunteer.**

I give clearance for:

**Mrs. Sylvia Anne Hoskins,
Maryvale Institute, Research Department, Old Oscott Hill, Kingstanding,
Birmingham, B44-9AG.**

- ☐ **To interview ONE registered nurse.**
- ☐ **Currently employed by the following private Care Home: (Name and address).**

I understand that my name and that of the Care Home will not be mentioned in any part of the research study (apart from my witness signature on the consent form) or made known publicly.

I also understand that the interviews are confidential and anonymous and that the name of the nurse will not be used in any part of the research study (other than signing a consent form) or made known publicly.

<u>Signature:</u>
<u>Date:</u>

Step 3 – The Process of Coding.

Eleven transcripts were individually analysed and coded.

Participant One

1. The first document, “Transcript of Interview” (Participant One), was brought onto the screen of the computer.
2. A second document was generated, titled “Code List”.
3. A third document was generated, titled, “Analysis of Interview and Coded Data”.
4. The researcher read the interview transcript (first document), searching for key words and indigenous phrases (relative to nursing) concerned with human actions and motions related to the ethical themes of freedom, responsibility and choice.
5. As the researcher identified each key word or indigenous phrase, it was allocated a code; for example “Accountability” or “Nurses’ Decision-Making”.
6. The newly identified code was transferred to document two, “Code List”. The Code was inserted in alphabetic order, with a corresponding numerical identity.

Thus, Code 1 = Accountability; Code 2 = Advocates; Code 3 = Age of Patient and issues relating. As each key word and indigenous phrase emerged and was identified and allocated a code, the researcher built a list of codes in the “Code List” (document two). This list remained as a numerical code list, which could be used as a reference point during the analysis process.

7. Each newly generated code, was then copied from the “Code List” (document two) and transferred to the “Analysis of Interview and Coded Data” document (document three). Within document three, each code was written as a title heading so that any emerging data with the key words or indigenous phrases, could be copied from the “Transcript of Interview” document (document one) and pasted onto the “Analysis of Interview and Coded Data” document (document three) under the representative code for that key word or indigenous phrase.
8. In the “Analysis of Interview and Coded Data” document (document three), the code headings were highlighted in bold and yellow colour and underlined, for easy identification by the researcher, during the analysis and coding process.

The researcher was thus working with three documents at one time:

1. Transcript of Interview.
2. Code List.
3. Analysis of Interview and Coded Data.

9. As each of the eleven transcripts was analysed and the data generated increased on the “Analysis of Interview and Coded Data” document (document three), the researcher frequently referred to the “Code List” (document two), to identify the number of the code. This assisted the researcher to transfer with ease the data to the “Analysis of Interview and Coded Data” document (document three).
10. Thus, the researcher would identify a key word or indigenous phrase, e.g. Spirituality, search the “Code List” (document two), identify the number and then search for the number on the “Analysis of Interview and Coded Data” document (document three). This system worked extremely well and saved the researcher from tedious searches for individual code headings in the “Analysis of Interview and Coded Data” document (document three).
11. Where the data in the “Transcript of Interview” document, (document one) generated several key words or indigenous phrases, the researcher copied and pasted the clump of data under several code headings in the “Analysis of Interview and Coded Data” document (document three).
12. In this way, the analysis of the interview transcripts was conducted systematically and methodically, in order to identify key words and indigenous phrases and generate codes. Although this process can be cumbersome, the researcher found this to be an extremely valuable exercise and allowed her the opportunity to become immersed in the data.¹
13. Participant One analysis generated fifty-eight codes.

Participants Two to Eleven

On completing the coding of Participant One transcript, the researcher proceeded to Participant Two transcript, which was downloaded onto the computer screen.

The researcher then downloaded the generated “Codes List” (document two) with its fifty-eight codes, copied and pasted the document to form “Analysis of Interview and Coded Data” document (document three) for Participant Two.

During the analysis process of Participant Two’s “Transcript of Interview” (document one), any new key words or indigenous phrases identified were given a new code, were added to the “Codes List” (document two) and the “Analysis of Interview and Coded Data” List (document three).

In this way, the researcher operated with three word documents at one time, analysing the data from each transcript in turn, whilst building up the “Code List”.²

It was during the next stage, the process of categorising the coded data, that the researcher identified twenty-one codes, which were merged with other codes and four codes, which were discarded, since they were irrelevant or repetitive. Seventy-seven codes emerged for categorisation.

Once the data were transferred into the identified categories, the researcher printed out the entire categories and corresponding codes. She then reviewed and scrutinised the data to identify any codes that had been allocated to a category, incorrectly. It was at

¹ Polit, D., Beck, C. Nursing Research: Principles and Methods 7th ed. (2004) 576.

this point that twenty-seven codes were further merged into other codes. In total fifty codes were clustered into eight categories.

Identifying the Participants by tracking back.

As the codes were generated and used to form headings in “Analysis of Interview and Coded Data” document (document three), the researcher copied and pasted the relevant data from the “Transcript of Interview” document (document one) to the “Analysis of Interview and Coded Data” document (document three).

Each part of the data were given a participant identity.³

- Participant One = **P.1**
- Page Three of the “Transcript of Interview” Document = **(3)**.

Therefore, the data copied from the “Transcript of Interview” document (document one) and pasted to “Analysis of Interview and Coded Data” document (document three), were identified as, **P.1 (3)** (Participant One, page three).

By using an identity number, the researcher could:

- cross-reference the data at a later stage, if required,
- enable an “Audit Trail” to determine the validity of the data,
- determine a method where any future researcher, could replicate the process of managing the data in this way, during the coding process.
- identify the research participant easily, in the event that the participant wished to withdraw any part of his/her contribution prior to publication.

² Appendix XI

³ Polit, D., Beck, C. Nursing Research: Principles and Methods, 7th ed., (2004) 576.

Number of Codes Originally generated List

<u>Participant</u>	<u>Codes generated</u>	<u>Total Codes</u>
One	58	58
Two	11	69
Three	11	80
Four	9	89
Five	7	96
Six	1	97
Seven	2	99
Eight	1	100
Nine	0	100
Ten	2	102
Eleven	0	102

FROM THE ORIGINAL 102 CODES IDENTIFIED

TWO FURTHER ANALYSIS AND FILTERING PROCESSES TOOK PLACE

53 CODES WERE MERGED WITH OTHER CODES OR DISCARDED

TO FORM 49 CODES

<u>Codes</u>	<u>Merged with Code</u>	<u>Discarded</u>
Aggressive Treatment	Futile Care	
Basic Nursing Care	Nursing Care	
Caring	Nursing Care	
Commitment	Nurses' Feelings and Job Satisfaction	
Comfort Care	Nursing Care	
Comfortable	Nursing Care	
Compassion	Qualities of a Nurse	
Complaint	Relatives' Emotions	
Concern	Qualities of a nurse	
Control	Autonomy	
Dependence	Nursing Care	
Doctor and Decision-making	Dependency on Doctor's Decisions	
Disabilities	Nurses' Decision Making/Actions	
Discomfort	Patient, Physical Pain	
Empathy	Fellow Feeling	
Experience in Nursing	Years Trained	
Family Orientated/Break in Work Experience	Years Trained and Experience	
Feelings, Patient	Patient's Mental State.	
Initial Response, Relative	Relative or Friend Participation in Decision-making.	
Initial Response, Nurse	Nurses' Decision-making/Actions	
Judgments	Assessments	
Justice	Value of the Person	
Living Wills	Autonomy	
Love	Qualities of a Nurse	
Loyalty	Trust	
Maleficence	Conflict	
Mediator	Advocate	
Money		Discarded
Nurses Action	Fellow Feeling	
Nurses and Teaching Others	Tradition	
Nurses views on caring for elderly	Nurses Views on the Dying Process	
Patient and Issues about Death and Dying	Patient Knowing they are Going to Die	
Position in Organisation		Discarded

Privacy	Dignity	
Professionalism	Nurses' Emotions; Qualities of a Nurse.	
Rationality	Nurses' Decision-making/Action	
Reasoning	Nurses' Decision-making/Action	
Respect	Dignity	
Responsibility	Accountability	
Rewarding	Nurses' Feelings and Job Satisfaction	
Rituals	Tradition	
Sharing	Relationships	
Spiritual Care	Spiritual/Religious	
Staffing Levels – Impact on Care	Nursing Care	
Strength of Character	Qualities of a Nurse	
Trust: Doctor Nurse	Trust	
Trust: Relative/Staff	Trust	
Trust: Patient/nurse	Trust	
Truth	Trust	
Unexpected Illness		Discarded
Values	Conscience	
Vocations	Nurses' Feelings and Job Satisfaction	
Years trained	Experience in Nursing Homes	

FIRST ANALYSIS PROCESS

The Code List (77 codes) – after first analysis.

1. Accountability
2. Advocates
3. Aggressive Treatment
4. Assessment
5. Autonomy
6. Basic Nursing Care
7. Best Interests
8. Caring
9. Comfort Care
10. Comfortable
11. Community Response
12. Compassion
13. Complaint
14. Concern
15. Conflict
16. Conscience
17. Consent
18. Coping Mechanisms
19. Dignity
20. Doctor and Decision-making
21. Duty
22. Decision-making and Clients/Patients with Alzheimer's Disease
23. Empathy
24. Ethos
25. Family Orientated, Break in Work experience (determines character)
26. Fear
27. Fellow-feeling
28. Futile Care
29. Grief
30. Guilt
31. Hope
32. Hydration/Nutrition (Decisions relating to)
33. Intuition
34. Justice
35. Knowledge
36. Living Wills
37. Loyalty
38. Maleficence
39. Mediator
40. Medication (Decisions relating to)
41. Money
42. Nursing Action
43. Nurses' Belief Systems
44. Nursing Care
45. Nurses and Decision-making

46. Nurses' Emotion
47. Nurses' Feelings and Job Satisfaction
48. Nurses' Feelings of Inferiority to a Doctor
49. Nurses' Views on the Dying Process
50. Nurses and Teaching Others
51. Nurses' Role
52. Patient Knowing They are Going to Die
53. Patient's Mental State
54. Patient's Physical Pain
55. Peace
56. Personhood – Nurses' understanding of.
57. Position in Organisation
58. Privacy
59. Professionalism
60. Quality of Life
61. Qualities of a Nurse
62. Reasoning
63. Relatives' Emotions
64. Relative or friend Participation in Decision-making
65. Relationships
66. Respect
67. Responsibility
68. Sharing
69. Spiritual Care
70. Spiritual/Religious
71. Staffing Levels – Impact on Care
72. Suffering
73. Traditions/Rituals
74. Trust
75. Value of Person
76. Views of nurses on caring for the elderly
77. Years trained and Experience in Nursing Homes (years)

SECOND ANALYSIS PROCESS

The Final Code List (49 codes)

1. Accountability
2. Advocates
3. Age of patient and Issues Relating
4. Assessment
5. Autonomy
6. Best Interests
7. Community response
8. Conflict
9. Conscience
10. Consent
11. Coping Mechanisms
12. Decision-making and Patients with Alzheimer's Disease
13. Dependency on Doctor's Decision
14. Dignity
15. Duty
16. Ethos
17. Fear
18. Fellow-Feeling
19. Futile Care
20. Grief
21. Guilt
22. Hope
23. Hydration/Nutrition (Decisions relating to)
24. Intuition
25. Knowledge
26. Medication (Decisions relating to)
27. Nurse' Belief System
28. Nursing Care
29. Nurses Decision-making
30. Nurses' Emotions
31. Nurses' Feelings and Job Satisfaction
32. Nurses' Feelings of Inferiority to a doctor
33. Nurse's Role
34. Nurses' Views on the Dying Process
35. Patient Knowing they are Going to Die
36. Patient's Mental State
37. Patient's Physical Pain
38. Peace
39. Quality of Life
40. Qualities of a Nurse
41. Relatives' Emotions
42. Relative or Friend Participation in Decision-making
43. Relationships
44. Spiritual/Religious
45. Suffering

- 46. Traditions/Rituals
- 47. Trust
- 48. Value of Person
- 49. Years trained and Experience in Nursing Homes (years)

These forty-nine codes were then clustered into piles of similar meanings to form eight categories.

EIGHT CATEGORIES

(49 Codes clustered into piles of similar meaning)

1. The Dying Process

- 1.1 Nurses' Views on The Dying Process
- 1.2 Patient Knowing They are Going to Die
- 1.3 Patient's Mental State
- 1.4 Patient's Physical Pain
- 1.5 Relative or Friend Participation in Decision-making
- 1.6 Relationships
- 1.7 Suffering
- 1.8 Traditions/Rituals

2. Spirituality

- 2.1 Spirituality, Religion
- 2.2 Nurses' Belief Systems
- 2.3 Ethos

3. Nurses' Professional Decision-making

- 3.1 Nurses' Decision making
- 3.2 Nurse's Role
- 3.3 Knowledge
- 3.4 Intuition
- 3.5 Assessment
- 3.6 Age of Patient and Issues Relating
- 3.7 Futile care
- 3.8 Decision Making and Patients with Dementia
- 3.9 Dependency on Doctor's Decision
- 3.10 Years Trained and Experience in Nursing Homes
- 3.11 Medication (Decisions relating to)
- 3.12 Hydration/Nutrition (Decisions relating to)

4. Emotions

- 4.1 Relatives' Emotions
- 4.2 Fear
- 4.3 Guilt
- 4.4 Hope
- 4.5 Grief
- 4.6 Peace
- 4.7 Nurses' Emotions
- 4.8 Nurses' Feelings and Job Satisfaction

5. Duty to a Patient

- 5.1 Duty
- 5.2 Accountability
- 5.3 Trust
- 5.4 Advocacy
- 5.5 Best Interests
- 5.6 Conscience

6. Patients Rights

- 6.1 Autonomy
- 6.2 Consent
- 6.3 Dignity
- 6.4 Value of Person
- 6.5 Quality of Life

7. Difficulties

- 7.1 Conflict
- 7.2 Nurses' Feelings of Inferiority to a Doctor
- 7.3 Coping Mechanisms

8. Support

- 8.1 Nursing Care
- 8.2 Qualities of a nurse
- 8.3 Community Response
- 8.4 Fellow Feeling

Theme I – (Main Theme)

Caring for the relatives and the staff whilst ensuring the patients' needs are met and

that they die in peace surrounded by love.

Categories:**1. The Dying Process:**

- 1.1 Nurses' Views on The Dying Process**
- 1.2 Patient Knowing They are Going to Die**
- 1.3 Patient's Mental State**
- 1.4 Patient's Physical Pain**
- 1.5 Relative or Friend Participation in Decision-making**
- 1.6 Relationships**
- 1.7 Suffering**
- 1.8 Traditions/Rituals**

2. Spirituality:

- 2.1 Spirituality, Religion**
- 2.2 Nurses' Belief Systems**
- 2.3 Ethos.**

3. Nurses' Professional Decision-making:

- 3.1 Nurses' Decision-making**
- 3.2 Nurse's Role**
- 3.3 Knowledge**
- 3.4 Intuition**
- 3.5 Assessment**
- 3.6 Age of Patient and Issues Relating**
- 3.7 Futile Care**
- 3.8 Decision-making and Patients with Dementia**
- 3.9 Dependency on Doctor's decisions**
- 3.10 Years Trained and Experience in Nursing (Care) Homes.**
- 3.11 Medication (Decisions relating to).**
- 3.12 Hydration and Nutrition (Decisions Relating to).**

4. Emotions:

- 4.1 Relatives' Emotions
- 4.2 Fear
- 4.3 Guilt
- 4.4 Hope
- 4.5 Grief
- 4.6 Peace
- 4.7 Nurses' Emotions
- 4.8 Nurses' Feelings and Job Satisfaction.

5. Duty to A Patient:

- 5.1 Duty
- 5.2 Accountability
- 5.3 Trust
- 5.4 Advocacy
- 5.5 Best Interests
- 5.6 Conscience.

6. Patient's Rights:

- 6.1 Autonomy
- 6.2 Consent
- 6.3 Dignity
- 6.4 Value of the Person
- 6.5 Quality of Life.

7. Difficulties:

- 7.1 Conflict
- 7.2 Nurses' Feelings of Inferiority to a Doctor
- 7.3 Coping Mechanisms.

8. Support:

- 8.1 Nursing Care
 - 8.2 Qualities of a Nurse
 - 8.3 Community Response
 - 8.4 Fellow Feeling.
-

Theme II - (Sub-Theme 1)

Nurses' responsibilities to ensure that the patient has adequate hydration and nutrition

during the dying process.

Categories:

1. The Dying Process:

- 1.4 Patient's Physical Pain**
- 1.5 Relative or Friend Participation in Decision-making**
- 1.6 Relationships**

3. Nurses' Professional Decision-Making:

- 3.7 Futile Care**
- 3.10 Years trained and Experience in Nursing (Care) Homes**
- 3.12 Decisions relating to Hydration and Nutrition.**

5. Duty to a patient:

- 5.3 Trust**
- 5.4 Advocacy**
- 5.6 Conscience.**

6. Patient's Rights:

- 6.5 Quality of Life**
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Theme III - (Sub-Theme 2)

Nurses being the advocates to ensure that medication is appropriate and meets the needs of the patients.

Categories

- 1. The Dying Process:**
 - 1.4 Patient's Physical Pain**
 - 1.5 Relative or Friend Participation in Decision-making**
 - 1.6 Relationships.**
 - 3. Nurses' Professional Decision-making:**
 - 3.1 Nurses' Decision-making**
 - 3.4 Intuition**
 - 3.5 Assessment**
 - 3.8 Decision-making and Patients with Dementia**
 - 3.10 Years Trained and Experience in Nursing (Care) Homes**
 - 3.11 Decisions relating to Medication.**
 - 4. Emotions:**
 - 4.3 Guilt**
 - 4.4 Hope.**
 - 5. Duty to a Patient:**
 - 5.2 Accountability**
 - 5.5 Best Interests**
 - 6. Patient's Rights:**
 - 6.1 Autonomy**
 - 6.2 Consent.**
 - 7. Difficulties:**
 - 7.1 Conflict**
 - 7.2 Nurses' Feelings of Inferiority to a Doctor.**
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